

## APPENDIX F. Data Limitations

### Limitations Crossing More Than One Chapter

#### Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS collects data on a variety of health risk factors, preventive behaviors, chronic conditions, and emerging public health issues. It is conducted continuously in all states as a collaboration between the federal Centers for Disease Control and Prevention (CDC) and state departments of health. The BRFSS is a telephone survey.

- The landline telephone portion of the survey has been conducted in Massachusetts since 1986; a cell phone component was not added until 2011. The CDC does not recommend using BRFSS data from 2011 and onward to show a trend or to compare with data collected prior to 2011.
- The BRFSS is limited to adults ages 18 and older residing in a private residence or college housing.
- Persons with the most severe limitations and with certain disabilities are not represented in this survey since individuals living in institutions are not included in the BRFSS. BRFSS methodology also precludes anyone from assisting respondents in completing the interview if the selected adult had difficulty in participating for any reason, such as an intellectual or developmental disability.
- The BRFSS is offered only in English, Spanish, or Portuguese.
- All data from BRFSS are self-report and cross-sectional.

#### Massachusetts Youth Risk Behavior Surveillance System (YRBSS) and Massachusetts Youth Health Survey (YHS)

YRBSS and YHS collect data on multiple topics relevant to adolescent health – diet, physical activity, alcohol, tobacco and drug use, behaviors related to unintentional injuries, violence, sexual behaviors related to unintentional pregnancy and STDs, and mental health.

- The YRBSS and YHS are pencil and paper surveys.
- They are administered to randomly selected schools and only in odd-numbered years.
- The YRBSS and YHS are limited to middle and high school students.
- YRBSS has been conducted in MA since 1993; YHS was first conducted in 2007.
- The YRBSS and YHS are administered only in public schools.
- Students who have severe limitations or disabilities, or who have frequent absences from school may be under-represented.
- All surveys are only administered in English.
- All data collected are self-report and cross-sectional.

#### Sexual Orientation and Gender Identity (SO/GI)

Massachusetts has been a national leader in monitoring the health of its residents along the lines of sexual orientation, adding a question about the sex of sexual partners (“sexual behavior”) to the Youth Risk Behavior Survey (YRBS) in 1993, and a question about sexual orientation identity in 1995. In 2000, a question about sexual behavior on the adult Behavioral Risk Factor Surveillance Survey (BRFSS) was added and a year later, a question to assess sexual orientation identity was added. In 2007, Massachusetts again demonstrated leadership and

included a transgender status question to identify transgender and cisgender respondents on the adult BRFSS, expanded in 2013 and adopted by the Centers for Disease Control for inclusion in the national BRFSS survey (optional lesbian, gay, bisexual and transgender module), the Youth Risk Behavior Surveillance System (YRBSS), and the Youth Health Survey (YHS). Health inequities by sexual orientation and gender identity (SO/GI) have been observed in all domains of health: safety, mental health, substance use, sexual health, and health care access. In 2017, the MDPH published a set of standards for SOGI data collection. These address the absence of a self-report question about assigned sex at birth on the BRFSS and YHS.

Where applicable, collecting sexual orientation, gender identity, and expression is increasingly becoming a standard in health care. MDPH has developed and will implement SO/GI data collection standards to ensure public health providers better understand patient needs, decrease invisibility, and improve the quality of care through communication, best practices, and interventions to reduce and eliminate health disparities. Massachusetts is actively working to improve health surveillance by modifying data collection tools and practices that are within the Department's domain.

- Instances of the word “sex” as a demographic category may be found in this report, which may in fact capture an individual's gender identity and/or expression regardless of their biological or anatomical designation at birth.
- The terms gender and sex are often used interchangeably by many of the data collection systems the Department must utilize, although they reflect different constructs and, thus, should be assessed with different questions.
- The need for valid measures of gender and a national data standard for sex have been acknowledged by the Institutes of Medicine, the US Department of Health and Human Services, and the Centers for Disease Control and Prevention.

## Chapter 1: Population Characteristics

- There are limited data sources for specific communities that make comprehensive analysis difficult, for example, the LGBTQ adult population, Immigrants, veterans, people with disabilities, and rural communities.
- Until MDPH can link their datasets, limitations will exist for generating a comprehensive analysis and evaluation of programs that can focus on many communities that includes descriptive statistics, the tracking of changes in health indicators and quality improvement.
- Mortality data sources do not currently include the race/ethnicity ancestries that meet standard MDPH expectations.

## Chapter 2: Maternal, Infant, and Child Health

### Breastfeeding

- There are limited real-time data on breastfeeding for mothers who are not WIC participants, particularly regarding duration and exclusivity; the National Immunization Survey (NIS) doesn't ask about breastfeeding practices until the child is 18 to 36 months old, which can make accurate recall difficult.

### Infant Mortality

- Data are limited on factors that contribute to the persistent racial/ethnic disparities in infant mortality.

- Surveillance systems lack standardized measures on racism and health inequities to discern their effects over the life course and across generations.

### Perinatal Substance Exposure

- No universal screening or testing of pregnant women is available from obstetric practices or hospitals to allow for accurate assessment of the prevalence of perinatal substance use.
- Inconsistencies exist in reporting cases of neonatal abstinence syndrome (NAS) at the hospital level because hospitals do not have universal screening or testing procedures and have different definitions of NAS.

### Sudden Unexpected Infant Death

- Population-based surveillance data are not available on sleep practices following the two- to six-month postpartum period.
- Existing data do not include community members' perspectives on infant safe sleep practices and post-discharge follow-up among preterm infants.

### Nutrition

- Limited information is available about overweight and obesity prevalence among students in private schools.
- Data reported to MDPH are limited to the school district level; data at a more granular level (e.g., by school or neighborhood) are not routinely collected across the state.

### Social/Emotional Health

- The inability to link Early Intervention (EI) program participation data to long-term school outcomes data restricts understanding of the benefits of EI on the social and emotional development of children.
- Data about parental mental health and well-being and adverse childhood experiences (ACES) are lacking in surveys of youth.

### Immunizations

- Comparing coverage across specific population groups within Massachusetts is difficult because low response rates to the NIS limits reliability and precision.

### Care within a Medical Home/ Support for Effective Care Transition

- Due to significant changes in the mode of data collection and sampling frame, 2016 data from the National Survey of Children's Health (NSCH) cannot be compared to prior years; 2016 data serve as a new baseline.
- Data are not yet available to examine state-specific 2016 NSCH indicators by select demographic characteristics (e.g., race/ethnicity, insurance status, etc.)

### Prenatal Care

- The Adequacy of Prenatal Care Utilization Index is based on the timing of the first visit and the number of visits completed, not necessarily the quality of care received.
- Limited data are available on how women are treated during pregnancy care by race/ethnicity and how that may impact treatment outcomes.
- Prenatal providers are required to send prenatal care records to birth hospitals at 24 weeks gestation but often do not update those records which can lead to undercounting of visits.

- There have also been issues with individual hospitals reporting limited or incomplete data due to technical difficulties, including the transition between electronic medical record systems. Data from those hospitals are not included in this report.

### Pregnancy Intention

- The Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) survey asks respondents about pregnancy intention only in even-numbered years.
- Only 2012 through 2014 data from the Massachusetts Pregnancy Risk Assessment Monitoring System (PRAMS) have been included in this report because the relevant question was revised in 2012 and cannot be compared to previous years.
- The PRAMS survey is only offered to women who had live births. Therefore, pregnancy intention results do not estimate how many total pregnancies are unintended, but only among pregnancies that had a live birth.

### Severe Maternal Morbidity

- Severe maternal morbidity surveillance uses administrative data created for billing purposes which sometimes lacks complete and accurate coding and can have limited information about disease severity.

### Pregnancy-Associated Mortality

- Data are limited on deaths that occur during pregnancy or following an early pregnancy loss or termination because pregnancy status may not be known or documented.
- The maternal mortality review process is based on evidence from medical records, vital records and public records that do not always capture important qualitative information about the deceased person's social environment.

## Chapter 3: Environmental Health

### Public Health Fish Advisories

- The majority of Massachusetts waterbodies have not been tested for the presence or concentration of chemicals in fish.
- Limited information is available about local fish consumption rates (how many and which population groups are eating the fish from an advisory area), making it difficult to assess the magnitude of health impacts.

### Ambient Air Quality

- The relationship between ambient concentrations of airborne contaminants and personal exposure is difficult to estimate and variable depending upon pollutant, activity patterns, and micro-environments.
  - Environmental measures do not necessarily equate to the amount of actual exposure or to the magnitude or severity of risk associated with potential exposures in a given area.
  - Variations across geography may not always be captured because data are only available from counties where monitors are located and these tend to be urban areas.
  - Air quality monitoring data may not coincide with health outcome data because of differences between the measurement and the exposure or the lag time between the exposure and symptoms.
- Ozone data are aggregated across the state and do not account for variations in levels of ozone between regions due to emissions sources, population density, meteorology, topography, and geography.

- Uncertainties exist in modeled air quality estimates and in projections of future air quality or climate effects.
- In evaluating the impact of ambient air quality on rates of disease like asthma, consideration of other determinants of respiratory health such as smoking, occupational exposures, and access to health care should be taken into account.

### Recreational Water Quality

- The analytical methods for fecal indicator bacteria include a lag time of at least 24-hours between sample collection, analysis, and results.
- Recreational water quality samples are generally collected on a routine schedule irrespective of potential drivers of exceedances, such as rainfall.

### Public Drinking Water Quality

- If a water system has a violation, it is not known if the entire water system was affected or only a part.
- Measures of the number of persons served by community water systems are estimates.
- It is difficult to quantify the exact number of people affected by a drinking water contaminant due to variation in consumption and susceptibility among the population.
- Data are not readily available for drinking water quality from private wells because testing is the responsibility of the private well owner.

### Childhood Lead Exposure

- Childhood lead poisoning screening rates are calculated based on population estimates using US Census data, and may not accurately reflect changes in population since 2010.
- Screening rates reflect the percentage of children aged 9-47 months who are tested for blood lead annually according to state guidelines; rates do not reflect the percentage of children ever screened between the ages of 9 and 47 months.
- Childhood blood lead level screening rates do not provide insight into the barriers that contribute to low screening in certain communities or why some children may not be screened each year.
- Race/ethnicity data is based on birth certificate information and is only available for children born in Massachusetts.
- Blood lead level rates in small communities or those with few children screened have a large margin of error.

### Heat Stress

- Heat stress data include all cases where heat stress is listed as the primary diagnosis or any other diagnosis in the hospital discharge databases, but does not include cases where heat stress is not listed as a diagnosis by the medical provider.
- Heat stress hospitalization data do not include individuals who are not hospitalized, including: deaths; those treated in outpatient settings; and some specialized hospital populations such as the Veterans Health Administration, Indian Health Service, and institutional populations.
- By focusing exclusively on the warmer months from May 1 to September 30, indicators of heat stress may miss changes in heat-related illnesses that occur in other parts of the year.
- Increased heat alone is not the only factor that can affect trends in “heat-related” hospitalizations. Vulnerability of a population due to factors like age and existing illness; geographic factors like climate, topography, and urbanicity; the extent to which people have adapted to higher temperatures; and the

steps people have taken to manage heat emergencies effectively can impact heat-related hospitalization rates.

### Environmental Justice

- Health data measuring a population’s potential vulnerability to environmental hazards are not available at the geographic level needed to effectively evaluate all potential indicators of vulnerability in environmental justice populations.

### Adult Lead Exposure

- Case counts of elevated blood lead levels reported to the Occupational Lead Poisoning Registry are considered minimum estimates of the actual magnitude of the problem because not all occupationally exposed adults are tested.
- Information about sources of lead exposure for adults in Massachusetts is not routinely collected for all cases.
- Information about race/ethnicity as well as a worker’s occupation and industry is incomplete and, therefore, summary statistics are not routinely generated.

### Asbestos-Related Disease

- Asbestos abatement employers are required to provide medical monitoring for their employees, but there is no on-going public health surveillance program to collect medical records or exposure documents that might track exposure, protection, and disease over time for these workers.
- The Massachusetts Cancer Registry provides information about usual occupation and industry of some but not all mesothelioma cases. Better information is needed about the potential source of exposure to asbestos for those mesothelioma cases with no history of employment in known high-risk industries.
- Asbestos-related diseases have long latencies so current disease estimates may be due to exposures that were present in the past and may not provide information about current and emerging occupational hazards.

## Chapter 4: Infectious Disease

### Foodborne Diseases

- Data are from population-based surveillance and represent individuals with significant symptoms who sought care and had positive test results. Therefore, reports likely underestimate the burden of all infections.

### Healthcare-Associated Infections

- Data on infections are from 2 different sources:
  - Population-based surveillance with limitation as above.
  - Hospitals through enrollment in the National Healthcare Safety Network (NHSN) and subject to staff reporting in accordance with national protocols.
- Data from antibiograms
  - Mix inpatient and outpatient specimen results.
  - Represent only infections for which susceptibility testing was requested.

## Sexually Transmitted Disease, HIV, and Viral Hepatitis Infections

- The HIV/AIDS exposure mode indicates the most probable risk behavior associated with HIV infection. Assignment of exposure mode is done in accordance with Centers for Disease Control and Prevention (CDC) guidelines when multiple exposure modes are reported. MSM (Male-to-Male Sex) includes males who report sexual contact with other males and males who report sexual contact with both males and females. Please note the acronym MSM is also used to refer to “men who have sex with men”.
- Newly diagnosed HIV infections/cases include Massachusetts residents, persons diagnosed with HIV from 2012 to 2014, including those who were concurrently or subsequently diagnosed with AIDS. All HIV data are presented by the year of diagnosis, not the year of report.
- Descriptions by race and ethnicity should be interpreted with caution. These characteristics are frequently missing from laboratory reports. Specifically, for cases of chlamydia racial/ethnic frequencies have been for internal use only because a backlog of non-electronic case report forms has resulted in 62% of cases missing race/ethnicity information in 2016.
- Race/ethnicity references to white residents and black residents represent persons who are white non-Hispanic and black non-Hispanic, respectively. All references to Hispanic/Latino for race/ethnicity represent persons of Hispanic/Latino heritage regardless of race.
- STD case incidence calculations represent crude rates. STD incidence rate calculations use race/ethnicity values that redistribute unknown values according to proportions of cases with known values.

## Tuberculosis

- Identification of latent TB infection depends on those infected getting tested and reported. Reports of latent TB underestimate the burden of all infections. BIDLS has excellent case ascertainment for TB disease as we rarely identify unexpected transmission. Completeness of case information is high because all TB disease cases are under BIDLS case management for a year or more.

## Vectorborne Diseases

- Data are from population-based surveillance and represent individuals with significant symptoms who sought care and had positive test results. Therefore, reports likely underestimate the burden of all infections.

## Immunization

- Immunization coverage data are from the Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) survey and represent individuals self-reported responses to a telephone survey. Therefore, reports are subject to selection and recall biases.

# Chapter 5: Injury and Violence Prevention

## Childhood Unintentional Injury

- Data is lacking on state and local measures of socioeconomic status of children experiencing injuries.

- Surveillance data are lacking on individual-level registry information on sports-related concussions, including type of sport and injury details that would allow for more targeted injury prevention efforts.

### Older Adult Falls

- Data are lacking about the location of injuries (e.g., home kitchen or yard) to assist advocates in tailoring prevention efforts.
- Data are fragmented on the incidence of falls in institutional settings such as assisted living or nursing facilities. Current data sources come from multiple agencies that provide health care at a range of institutional settings.
- Improved data are needed on the social and economic characteristics of persons who have fallen to better understand what groups experience a disproportionately high-risk for falls.

### Motor Vehicle Accidents

- Hospital and emergency department discharge data typically does not include information on certain risk factors such as texting and drug use.
- Most datasets do not include information on the geographical location of injury, limiting the ability to identify high-risk traffic areas.

### Non-Fatal Occupational Injuries

- Estimates of non-fatal occupational injuries from any one data source undercount the full extent of this issue; multiple data sources are needed to provide the most complete picture possible of the occupational health status of the population.
- Additional information is needed about the occupational injuries and health and safety experiences of workers employed through temporary staffing agencies and other non-traditional employer-employee relationships.
- Workers' compensation data are an important source of information on work-related injuries, but use of this administrative database is limited because data are not routinely coded for analysis.

### Fatal Occupational Injuries

- Although Massachusetts has a robust fatal occupational injury surveillance system, better identification is needed about work-related motor vehicle usage.
- More research is needed on the health and safety of temporary workers, including whether these workers are receiving the appropriate safety and health protections and training by both the temporary agencies and the host employers.
- More information is needed about effective strategies for reaching low wage immigrant and minority workers with health and safety messages and training.

### Suicide

- The number of suicide deaths is under reported. The most likely causes include stigma, misclassification of deaths as undetermined, and misclassification of overdose deaths.
- The Massachusetts Violent Death Reporting System is limited by the information collected from death certificates, medical examiner files, and police reports, resulting in a potential undercount in some



demographic and circumstantial areas such as gender identity, sexual identity, and socio-economic status.

## Youth Violence

- Limited data are collected over multiple time points about youth development and youth violence.
- Additional research is needed on the intersections of gender, trauma, and youth violence, including girls in gangs, sexual assault, increased incarceration, and bullying.
- Research is needed on the intersections of youth violence and bullying, emerging trends in violent extremism, child maltreatment or adverse childhood experiences (ACES), increases in opioid use among youth, poverty, school discipline for youth of color, including school expulsions, youth incarceration, and juvenile detention.
- Improved understanding is needed about the roles of policies and digital policing on youth violence.
- The Massachusetts youth surveys (Massachusetts Youth Risk Behavior Survey (MA YRBS) and Massachusetts Youth Health Survey (MA YHS)) do not obtain data from youth who are not in school for any reason, or from youth who are unable to independently complete a paper-and-pencil survey using a scantron sheet.
- The youth surveys (MA YRBS and MA YHS) are subject to the limitations of self-report data, which include impression management, self-deception, and memory limitations that arise from normal human cognitive processes.

## Homicide and Assault

- The Massachusetts Violent Death Reporting System is comprised of data from death certificates, medical examiner files, and police reports; resulting in an undercount in some demographic and circumstantial information due to a lack of information in a victim's record.
- The Massachusetts Violent Death Reporting System does not capture information on socio-economic status and past exposure to violence that would be helpful in better understanding the role of social determinants of health in homicide deaths.

## Sexual Violence/Child Sexual Abuse

- More research is needed on understanding of the multilevel factors that contribute to the risk of sexual violence to help identify opportunities for prevention.
- Research has established links between women's sexual assault experiences and behavioral and reproductive health, but more longitudinal research is needed to document the timing of sexual violence victimization and these health outcomes.
- Since most studies on sexual assault focus on small convenience samples of women (such as patients), more research is needed with a broader representative sample of women.
- With the exception of data from a health survey of high school students, Massachusetts-based research does not include detailed data about child victims of sexual abuse or demographic information about the abuser, the race/ethnicity of the victims, and the age of the victims.
- The Massachusetts Behavioral Risk Factor System (MA BRFSS), a health survey of adults ages 18 and older in Massachusetts, does not capture data from adults living in institutional settings, homeless adults, adults without telephone service, or adults who are unable to answer survey questions

independently because of a developmental or intellectual disability or a communication disability. Adults who do not speak English, Spanish, or Portuguese also are not represented in the MA BRFSS data.

- The Massachusetts youth surveys (Massachusetts Youth Risk Behavior Survey (MA YRBS) and Massachusetts Youth Health Survey (MA YHS)) do not obtain data from youth who are not in school for any reason, or from youth who are unable to independently complete a paper-and-pencil survey using a scantron sheet.
- Both the adult survey (MA BRFSS) and the youth surveys (MA YRBS and MA YHS) are subject to the limitations of self-report data, which include impression management, self-deception, and memory limitations that arise from normal human cognitive and social-cognitive processes. In the case of stigmatized and traumatic experiences in particular, these processes can result in under-reporting.

## Domestic and Dating Violence

- Massachusetts currently relies on a national survey conducted by the Centers for Disease Control and Prevention (CDC) for state-level estimates of intimate partner violence among adults, but this data lags several years behind the current calendar year.
- Limited data are collected on people with disabilities and their experience of domestic violence; little is known about the perpetrators of domestic violence against people with disabilities.
- Limited data are collected on perpetrators of domestic violence against people in other high-risk populations, including data on the gender and sexual orientation of perpetrators against victims who identify as LGBTQ. The Massachusetts youth surveys (Massachusetts Youth Risk Behavior Survey (MA YRBS) and Massachusetts Youth Health Survey (MA YHS)) do not obtain data from youth who are not in school for any reason, or from youth who are unable to independently complete a paper-and-pencil survey using a scantron sheet.
- The youth surveys (MA YRBS and MA YHS) are subject to the limitations of self-report data, which include impression management, self-deception, and memory limitations that arise from normal human cognitive and social-cognitive processes. In the case of stigmatized and traumatic experiences in particular, these processes can result in under-reporting.
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## Chapter 6: Addiction

- Massachusetts currently does not have a comprehensive statewide youth health survey for establishing baseline prevalence estimates.
- Health surveys do not reach some populations who are at high-risk of substance use; for example, substance use assessments do not reach all schools and community organizations.
- Description of Bureau of Substance Addiction Services (BSAS) Data Set: Under MGL Ch.111 B and E authority, all treatment providers are required to submit data to BSAS to carry out the responsibilities listed under the law. The regulations promulgated to carry out these responsibilities require the providers to submit data in a timely manner. The required data fields include but are not limited to: client characteristics, enrollment, disenrollment information, services and outcomes. Currently, only treatment providers that receive funding from the Department submit the required data to BSAS. BSAS uses this data for billing/payment and service planning purposes. Almost all BSAS licensed/contracted providers enter the required data through the Virtual Gateway. Assessment data collected at admission and disenrollment are entered into Enterprise Invoice Management/Enterprise Service Management (EIM/ESM) system daily or in batches. Data entry occurs at provider sites and is transmitted to BSAS on a monthly basis. The current database includes data from Fiscal Year 2000-2017. BSAS can readily report data at the provider level, the enrollment level, and the client level.
- The BSAS data set poses several limitations. First, BSAS data does not represent all substance abuse treatment provided in the Commonwealth. BSAS only collects data from its contracted providers. Of the data that is submitted to BSAS, outpatient treatment data is incomplete and does not include all non-BSAS paid services. BSAS does not collect data from providers that prescribe Naloxone or from non-contracted Buprenorphine providers. At the time of this report, Methadone data was incomplete. Due to challenges associated with recent system changes related to data submission, some Methadone providers have been unable to submit data. Data collected in regards to section 35 commitments are incomplete in the BSAS data set. As a result of these data limitations, it is possible that some of the analyses using BSAS treatment data may provide an incomplete picture of substance abuse treatment in the commonwealth.
- BSAS does not collect data from all sites that administer medication assisted treatment across the commonwealth. BSAS receives data for methadone and subset of buprenorphine providers that we fund. BSAS does not receive data for other FDA approved medications used to treat alcohol use disorders (i.e. Acamprosate and Disulfiram).

### Intervention

- The state does not currently require information on the number of individuals who have been screened or have received brief intervention, or the number of practices or health care settings that routinely screen their patients.
- MDPH received one-time funding to include in the 2014 Behavioral Risk Factor Surveillance System survey questions about physician screening and discussions about substance use with patients, but this information is not routinely collected.

### Narcan

- Available data are from MDPH-funded programs only, and do not include data from pharmacies or from all first responder departments that provide naloxone.

- Data collected from the Overdose Education and Naloxone Distribution (OEND) Bystander Program is reported by the bystander witness and has no information regarding the individual who experienced the overdose.

## Treatment

- Treatment program utilization data does not include opioid treatment programs in office-based settings and level IV acute care facilities.
- Treatment program utilization data is not fully representative of access to treatment services due to lack of knowledge by the individual or improper triage or referral by the provider.
- Lack of follow up data on individuals who completed treatment prevents assessment of long term treatment outcomes.

## Recovery Support

- Longitudinal data that follow individuals over time is not available to assess the longer-term impacts of recovery support centers and/or how recovery support services improve outcomes for clients.

## Youth Population

- Massachusetts does not implement comprehensive statewide health surveys that reach out to all youth and or young adult populations.
- Treatment data are only collected from BSAS funded and/or licensed substance treatment programs.

## Pregnant Women

- Pregnancy status data are collected once during an initial treatment admission, but gaps exist in periodic reporting of change in status for women who become pregnant and post-partum women while in treatment.

## Criminal justice

- Criminal involvement among the treatment population is self-reported.
- There is a lack of data sharing regarding substance use among criminal justice population across state agencies.

## LGBTQ

- Large data sets that may enhance understanding of the experiences and needs of LGBTQ youth and young adults are not currently available.
- Validated assessment tools have not been adequately tested with LGBTQ populations.
- Research studies on the LGBTQ community often cannot be compared because of inconsistent methodologies.
- Research on the effectiveness of various recovery pathways within LGBTQ communities is limited.

## Military

- BSAS may underestimate the number of veterans they serve.

## Homeless Population

- Many assessments tend to focus on individuals who stay in shelters or attend soup kitchens.
- Individuals who experience temporary housing instability are likely to be missed in many assessments.

- The definition used for classifying people as homeless substantially affects the estimate of the homeless population.

## Mental Health

- Individuals with differential acuities between their co-occurring disorders might only access treatment for their most acute issue; if they have a more severe mental illness compared to their substance use disorder, they might only receive mental health services. These individuals would not be adequately represented in BSAS data. The pilot programs with the Department of Mental Health aim to cover this limitation in future assessments and ensure that individuals receive all needed services.

## Gambling

- There are several limitations of available data regarding gambling. First, there is a general underreporting of gambling disorder in the Bureau of Substance Abuse Services (BSAS) system, as well as in national prevalence studies. Accordingly, national studies are limited in their ability to estimate the percent of the population who are currently in treatment for gambling-related issues. Second, SEIGMA has a low response rate (36.6%), and findings may not be generalizable. Third, the measures used in the SEIGMA to screen for gambling have not been validated using the DSM-5 criteria with adult samples, with implications for the extent to which gambling disorders are captured.

## Chapter 7: Health Systems and Health Care Access

- Data limitations exist for health care workforce data sources that do not always include some health care providers who are also important when evaluating a community's capacity (i.e. EMT technicians, social workers, physician assistants).
- Data limitations exist for GPS mapping of vulnerable populations that would enable preparedness and emergency management responders to plan more efficient delivery of services around transportation and other unique needs during emergencies for these populations (i.e. people with a disability or chronic disease).
- Data sources exist for evaluating health care access, safety, timeliness, and other considerations but limited access to them as well as the need to build capacity to analyze them remains a challenge (i.e. All Payer Claims Database or Electronic Medical Records).

## Chapter 8: Wellness and Chronic Disease

- Estimates of health behaviors and the prevalence of chronic disease across the Commonwealth are based on the Behavioral Risk Factor Surveillance System (BRFSS), but due to a new sample weighting methodology, trends after 2011 cannot be compared to previous years.
- The limited BRFSS sample size among adults prevents more sophisticated sub-group analyses.

## Nutrition

- MDPH has no available indicators on consumption of sugar-sweetened beverages for adults, an important indicator of nutritional practices and chronic disease risk.
- Fruit and vegetable consumption among adults is assessed every two years in the BRFSS presenting challenges to analyzing trends in dietary practices.
- The US Department of Agriculture Food Desert program provides only a partial snapshot of access to and affordability of healthy foods across the Commonwealth.

## Physical Activity

- Measures are lacking to evaluate the effectiveness of interventions and actions designed to create changes to the “built environment” and to reach all populations or geographies.
- The BRFSS does not adequately measure walking and biking behavior.
- The BRFSS is limited in its ability to examine overall physical activity behaviors at the local or sub-local level, where interventions need to be measured and evaluated.

## Adult Smoking

- Massachusetts Tobacco Cessation and Prevention has limited information on tobacco use among high-risk groups including immigrants, veterans, and the homeless.

## Prevention/Other Tobacco Products

- Published evidence is lacking on the long-term impact of many Massachusetts point-of-sale policies.
- Local youth survey data on the impact of local policies on youth behavior because many school districts are unwilling to publicly share survey results on substance use.

## Second Hand Smoke

- Comprehensive data are lacking on the scope of smoke-free policies in multi-unit housing about residents living in low-income and Section 8 housing that are disproportionately exposed to secondhand smoke in the home.

## Adult Overweight and Obesity

- The BRFSS provides no information about sugar-sweetened beverage consumption among adults.
- BRFSS questions that ask about the types of physical activity that are most likely to contribute to healthy weight as well as fruit and vegetable consumption are asked only every other year, making it difficult to analyze trends.

## Child Overweight and Obesity

- Limited information is available about the prevalence of overweight and obesity among students in private schools.
- Data on body mass index, race/ethnicity, and gender are limited to data collected by school districts; Massachusetts does not collect data at a more granular geographic level.
- While data are available about children participating in the WIC program, there is no statewide mechanism for collecting BMI on children before school age.

## Cardiovascular Disease

- The variety of datasets available on hypertension, heart failure, heart attacks, and stroke provide an important lens into disparities in the burden of cardiovascular disease across the Commonwealth.
- Although these data are expansive and are used to research and evaluate many risk factors, clinical data systems do not consistently capture some social and economic factors that shape health and health disparities. However, this is changing, with a particular focus on improving income, socio-economic status, and racial data.

## Diabetes

- Diabetes risk factors and outcomes can be analyzed using a variety of data sources, providing detailed demographic and geographic stratifications.

- However, limited data are available about the prevalence of prediabetes (a critical risk factor for developing diabetes) due to a lack of knowledge about prediabetes and providers not always telling patients they have prediabetes.
- Clinical data systems do not consistently capture some social and economic factors that shape health and health disparities. However, this is changing, with a particular focus on improving income, socioeconomic status, and racial data.

### Asthma

- Delay in accessing the hospitalization discharge database and limited access to the All Payer Claims Database prevents analysis of more recent hospitalization data and/or examination of patterns by other social, economic, or geographic factors.
- Limited sample size of BRFSS Asthma Call Back Survey prevents additional subgroup analyses of children.

### Chronic Obstructive Pulmonary Disease

- Further research is needed to understand the social patterning of COPD as well as effective intervention strategies to improve COPD management.

### All Cancers

- Information is limited in the Cancer Registry about the socioeconomic status of individuals, including their household income levels, educational attainment, employment status, and health insurance status.
- The number of cancer cases at the local level is not large enough to examine cancer disparities locally by race/ethnicity, income, employment, and other social determinants of health.

### Lung Cancer

- Although Massachusetts hospitals screen for lung cancer following the establishment of new screening guidelines, lung cancer screening data for individuals is not published.
- BRFSS is used to assess the proportion of people screened for various cancers, including breast, cervical, and colorectal cancer; however, lung cancer questions are not included.
- The Lung Cancer Workgroup uses data from the American College of Radiology to track the number of facilities that are conducting lung cancer screening, but this information does not include the proportion of adults who are screened for lung cancer.

### Breast Cancer

- While cancer data are available at more granular geographic levels, the number of breast cancer cases at the local level is not large enough to examine cancer disparities locally by race/ethnicity, income, employment, and other social determinants of health.

### Colorectal Cancer

- Colorectal cancer screening data for Asians and Native Americans is not collected.
- The MDPH uses the Health Resources and Programs Administration (HRSA) data to monitor and evaluate the effectiveness of colorectal cancer initiatives in community health centers under the League of Community Health Centers, but these data are not stratified by social and demographic characteristics such as age, race, income, education, and insurance status.

## Prostate Cancer

- It is difficult to add questions to the BRFSS survey without increasing the length of the survey, adversely affecting the number of prostate cancer questions included in the survey.
- Because the BRFSS is a statewide survey, it is not possible to obtain shared decision-making data at the local level.

## Melanoma

- The Cancer Registry only reports melanoma incidence and mortality data for Massachusetts overall and for White non-Hispanics. The registry does not include data for other racial/ethnic groups because the numbers are deemed insufficient to track.
- A central place is needed to document the implementation of various melanoma initiatives throughout the Commonwealth.