Gender mainstreaming in emerging disease surveillance and response

Western Pacific Region

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Disclaimer

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Executive Summary

While uptake of gender mainstreaming has been slow and uneven across many public health professionals and bodies, the Division of Health Security and Emergencies at the Western Pacific Regional Office of the World Health Organization has worked towards greater gender awareness and sensitivity with vigour. While the Division of Health Security and Emergencies is in the initial stages of mainstreaming gender into its work, public health bodies that have made less progress in incorporating gender awareness can learn from this example.

The work of the Division has been conducted under the rubric of the Asia Pacific Strategy for Emerging Diseases (APSED). The vision of APSED is to minimize the health, economic, and social impacts of emerging diseases in the Asia Pacific Region. Over the past five years, APSED has become a widely used tool, guiding regional efforts to address the threat of emerging infectious diseases. Updated in 2010 on the basis of Member State recommendations and experiences during previous years and during the pandemic H1N1 of 2009, the current APSED strategy focuses primarily on emerging diseases, but seeks also to incorporate additional public health threats by identifying areas of synergy and special situations in which the strategy can make important contributions. As a basic component of descriptive epidemiology, analysis of all health data by time, place and person (including sex) is conducted under the APSED strategy. However, methods of documentation and analysis can vary by country. Gender issues are a primary consideration under the APSED 2010 strategy.

The current case study reveals the following points. Strong support from Regional Office and Division leadership were pivotal in carrying forward the cause of gender mainstreaming. Donor interest was also a key trigger catalysing the implementation of gender mainstreaming in the Division. Successful gender mainstreaming was also carried forward through staff interaction with gender experts and gender awareness training sessions for staff. These allowed staff to understand that systematic gender analysis of collected data can shed light on gender practices and allow for the improvement of responses to public health emergencies. The training sessions and interaction with gender experts also raised staff awareness of areas of routine work practice in which increased gender awareness and analysis would be particularly useful. Considerable planning and collectively agreed goal-setting for further activities to mainstream gender were also conducted during this process. Currently, not only is retrospective gender analysis conducted on previously collected disease and outbreak data
and the relevant findings disseminated, but gender analysis has also been clearly incorporated into the routine work of Division staff.

**Introduction**

Gender refers to the roles, behaviours, activities, and attributes that a given society considers appropriate for men and women. Sex, on the other hand, refers to biological differences between women and men. While gender differences are socially constructed, sex differences are not. While gender differences can change over time and are the result of societal sanction and disapproval regarding men’s and women’s behaviour, sex differences are relatively fixed. Gender differences include socio-cultural factors as well as male-female differences in access to and control over resources. Gender roles and relations can be helpful or detrimental to the health of men or women.

A major objective of gender analysis for infectious diseases is to identify the differences men and women face in access to and control over resources. Those gender-related roles and practices that put women and men at higher or lower risk of infectious diseases should be ascertained, so as to discourage harmful practices and encourage helpful ones. Considering male-female differences can increase the effectiveness of disease control programmes and the likelihood of programme success.

The following is a diagram\(^1\) depicting the impact of sex and gender on emerging infectious diseases. While sex affects biological susceptibility to disease, gender affects the typical roles and responsibilities of men and women, and thereby impacts the work- and activity-related exposure of men and women to disease. Clothing, mobility, family responsibilities, access to household finances, decision-making authority within the family, and levels of disease-related stigma can all differ by gender, and is therefore central to an understanding of susceptibility, exposure, vulnerability, and individual and community responses to disease.

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\(^1\) Anker, Martha. *Taking Sex and Gender into Account in Emerging Infectious Disease Programmes: An Analytical Framework.* World Health Organization Western Pacific Region, 2011.
United Nations organizations, academic institutions, and country governments increasingly view gender issues as central to the effectiveness of public health work. Major donors have also pushed for more systematic and stronger gender mainstreaming than was conducted in the past, while the World Health Organization (WHO) has established gender mainstreaming as a priority throughout its work worldwide. In keeping with this trend, the Division of Health Security and Emergencies at the Western Pacific Regional Office of WHO has made gender mainstreaming a priority in its work under the above-mentioned Asia Pacific Strategy for Emerging Diseases (APSED).

Over the past five years, APSED has become a widely used tool, guiding regional efforts to address the threat of emerging infectious diseases. Updated in 2010 on the basis of Member State recommendations and experiences during previous years and during the pandemic H1N1 of 2009, the current APSED strategy focuses primarily on emerging diseases, but seeks also to incorporate additional public health threats by identifying areas of synergy and special situations in which the strategy can make important contributions. The vision of APSED 2010 is to minimize the health, economic, and social impacts of emerging diseases in the Asia Pacific Region. Gender is considered to be a primary consideration in APSED 2010 implementation. While the uptake of gender mainstreaming in many public health professionals and bodies has been slow and uneven, the Division has worked under the rubric of APSED towards greater gender awareness and sensitivity with vigour.
Context / Problem Space

Many public health and disease programmes do not engage in systematic gender analysis. This is likely the result of a lack of awareness regarding the benefits of incorporating gender analysis into public health work. Moreover, the utility of available gender analysis tools may need to be properly understood and the tools utilised before tangible benefits may be seen. Prior to incorporating systematic gender analysis, the Division did not prioritise gender awareness as crucial to the success of its work. However, the Division collected many datasets that could have borne evidence of gender practices and could have further improved staff responses in public health emergencies. It was in response to donor interest that the first activities around gender awareness were implemented within the unit. Through growing interactions in gender training workshops and with gender experts, it became apparent that the manner in which Division data were collected and analysed was a primary arena within which gender mainstreaming should take place. Over time, the Division staff and leadership have come to view gender awareness and gender mainstreaming as central to the effectiveness of its work, and are now vigorously implementing activities around gender mainstreaming. The following is a description of the manner in which the Division’s work was routinely conducted prior to the onset of gender mainstreaming activities.

Data analysis work involves several types of analysis. Outbreak investigations are conducted in the event of a disease outbreak, and comprise investigations of cases, sources, and transmission of disease. Routine indicator-based surveillance (IBS) is periodic reporting of a defined set of indicators, such as, for example, the number of patients with bloody diarrhoea attending a given health facility each month. IBS reporting occurs through sentinel or notifiable disease surveillance systems, and is commonly composed of data reported from health facilities on a weekly or monthly basis. Additionally, event-based surveillance involves immediate reporting of unusual disease events. Sources of event-based surveillance reporting can be media outlets, community organizations, health facilities, health care organizations, universities, etc. Event-based surveillance is better than IBS at catching information on events not included in notifiable disease reporting systems and reporting on events more quickly.

The purpose of an outbreak investigation is to determine the possible source and route of transmission of disease, as well as risk factors for disease. In the event of an outbreak, investigation
by Division staff routinely includes analysis by time, place and person (including sex), as this is a basic component of epidemiological investigation.

With regards to IBS, some Member Countries analysed and reported data that were disaggregated by age and sex. Others collected and analysed disaggregated data, but reported only aggregated values to the Regional Office. Sex- and age-disaggregated data often existed at the local level, but were often not reported to the WHO Country Offices. However, if sex differences in disease risk occur only in some age groups, differences may not be observed at the aggregate level, and may only appear when the data are stratified. This is important because gender roles often change with age. Furthermore, at a national or regional level, sex- and age-disaggregated data could reveal more insights than are apparent at the local level. Thus, it was important to ensure that disaggregated data were reported to higher-level bodies throughout the reporting system and to the Regional Office.

Division staff had also not taken into account possible selection bias in the observed sex distribution of IBS data. Such bias may exist when gender norms and roles and/or men’s and women’s access to health care or health-seeking behaviour differ. Thus, even when an equal breakdown of men and women among reported cases of infection is observed, the given data could be missing a lot of women or a lot of men, or specific groups of men, women, boys or girls, due to differences among groups in health care access or health-seeking behaviour. Additionally, even accurate data revealing an equal sex distribution of disease may indicate that disease outcomes are abnormal and require an adjusted health care response. For example, in the case of tuberculosis (TB), a 2:1 male-female ratio is found everywhere. Thus, if a 1:1 male-female distribution were found, this should raise questions, and may indicate an inordinately high vulnerability or exposure for women. In particular, in the case of unknown or newly emerging diseases, an expected 1:1 sex distribution of cases should not necessarily be assumed. Moreover, the sex distribution of cases may also differ in later stages of an outbreak compared with earlier stages. Thus, it is important to conduct further sex and gender analysis even in the case of a 1:1 male-female breakdown of cases within reported data.

Even in the case of a disease in which men and women are equally at risk and for which accurate data reveal an equal sex distribution of cases, patterns of exposure may differ by gender. For example, women may work on small, unregulated backyard farms more frequently than men, and
therefore may be at increased risk of contact with poultry infected by avian influenza. Depending on country and context, investigators may find that women are responsible for tending backyard poultry and selling poultry in markets, while men are primarily employed in commercial poultry establishments. Alternatively, men may tend to sell poultry in markets in some societies, while in other societies women do so. Thus, routes of exposure to disease, patterns of health-seeking behaviour, provider and patient delay, and access to health services may all differ by gender. Communication messages, transportation of supplies, patient treatment, and other disease response activities must consider possible gender differences that could impact upon response efforts.

Initial Implementation

As a result of initial gender mainstreaming activities, Division staff realised they hold a lot of data that can improve gender-awareness in public health practice and responses in emergencies. They further realised the potential gender-related benefits of the data collection and analysis which is routinely undertaken. Subsequent planning for further activities to improve the state of affairs was implemented.

In September 2007, advice was provided on how to integrate gender into the programmatic components of the APSED 2005. Also in September 2007, a short orientation on gender and health was organized for technical staff of the Division. In March 2008, the document "Taking sex and gender into account in emerging infectious disease programmes: An analytical framework", which outlines a framework for gender analysis in emerging infectious diseases (EID), was drafted and presented to Division colleagues for review and suggestions. This document is now published, and is widely distributed at meetings and sent to country governments to raise awareness of gender in EIDs. The framework suggested in this document will be used by Division staff to conduct gender analysis. In September 2009, a session on gender was included during the annual meeting of national programme managers for EIDs. In September 2010, a regional workshop on mainstreaming gender in health security emergencies was held. This workshop included training of staff on the importance of gender and gender-mainstreaming. The workshop was also used to plan and set goals for further gender mainstreaming in the Division’s work. In follow up of the workshop, gender analysis

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tools were developed for use by Division staff during routine surveillance activities and during outbreaks.

**Planning**

The first stage of implementation of gender mainstreaming activities included the development of documents and several training sessions that allowed Division staff to gain an understanding of the importance of gender issues in public health work. Division staff also discussed how to move forward to further solidify the work of gender mainstreaming in the Division.

During planning for further gender mainstreaming, Division staff raised a number of points, including the following. Since basic epidemiology (time, place and person) is embedded in the Division’s work and investigation, routine gender analysis of this information can enhance decision making, communication, and interventions. Information to help epidemiologists and investigators during a crisis could be provided as a result of routine gender analysis. Time constraints do not allow for lengthy gender analysis during an emergency. However, when not in an outbreak or crisis situation, there is time to create an evidence base. At present, the evidence base on, for example, gender and dengue or gender and rabies, is lacking. Little information is available on the manner in which gender affects an outbreak. However, information from previous outbreaks could inform future outbreaks. Thus, there is a need to collect the relevant information and share it widely. Gender analysis of IBS data could be used to inform outbreak investigations and response activities.

Additional points raised by Division staff during the planning stage were as follows. Pregnancy is an important issue in gender analysis, as it can compound vulnerability. It is particularly important to collect pregnancy information for a newly emerging disease for which little information is available. In addition, it is important to remember that gender issues are not only women’s issues. Men's gender norms, roles, and gender-based division of labour and their links to health dimensions such as vulnerability to infection, health care seeking behaviour, and experience in health care settings should also be analysed.

Subsequent to collective discussion among Division staff, the following action points were agreed. (1) ESR country teams will provide datasets disaggregated by sex and age, for selected diseases where
such data are available. These datasets will be analysed at the Regional Office. Regional Office analysis will thereafter be shared with countries so as to increase country-level awareness of gender differences with regard to the selected diseases. (2) During an outbreak situation, data that are reported should include the sex of those reported to have infections. (3) In indicator-based surveillance (IBS), data should always be reported on an age- and sex- disaggregated basis. These data will undergo sex and gender analysis, and the findings reported. (4) These findings from IBS analysis will also be used to inform outbreak investigation and response activities. (5) Gender analyses, using available tools, will be conducted yearly or every other year to support Division work at the country level.

Additionally, Division staff agreed to take into account possible selection biases that may be in operation in surveillance data as a result of gender norms and roles and men’s and women’s differential access to health services. Staff agreed to be mindful of this and other gender issues during data analysis.

Below is found a diagram depicting both the Division’s previous pattern of data collection and analysis as well as current gender mainstreaming goals.
A snapshot of the current and possible future practice of disease surveillance in emerging infectious diseases (EID)

Current practice in outbreak investigation

- Data disaggregated by sex sometimes reported; sometimes dismissed

Gender-responsive future practice in outbreak investigation

- ALWAYS report data disaggregated by sex; Never dismiss

ALWAYS report data disaggregated by sex in outbreak reports
Implementation – 2nd Stage

Currently, Division staff systematically look for gender-related trends in data when received data include the age and sex of cases. Retrospective quantitative analysis of sex- and age-disaggregated dengue and leptospirosis data from several countries, as well as data on various diseases in the Philippines, has also been conducted by Regional Office staff. Additionally, Division staff now collect outbreak reports with sex-disaggregated data whenever possible. Countries have been encouraged to report such data. New outbreak and IBS data are now reported largely on a disaggregated basis where available. Far more IBS data are now reported with sex and age information than before. In locations where this data is not yet available, the relevant countries are urged to consider this important aspect for future practice.

Interesting and potentially significant findings are emerging from this analysis. Listed below are a few examples of the type of gender analysis now commonly conducted by the Division team.

Analysis of IBS data from 4 countries showed that dengue is a prime example in which gender, under certain conditions, modifies risk. In Singapore, for example, more dengue cases are reported among adolescents and adults than among the very young (<5 years of age) or the elderly (>55 years of age)\(^3\)\(^4\). Since men predominate in outdoor work sites, nearly twice as many men are infected with dengue than women in working-age groups. Among the very young and elderly, males and females both spend more time at home, and no such gender difference is observed\(^3\). Similarly, in the Philippines, where the majority of cases are reported for those between the ages of 1 and 20 years of age, more males than females are infected with dengue among young, working-age groups (aged 11-20 years and 21-30 years, and to a lesser extent among those aged 31-40 years)\(^6\). As with Singapore,


\(^6\) Philippines Department of Health, 2010 (personal communication)
there is no difference by gender among young children (those <11 years of age) and the older age groups (those greater than 40 years of age). Thus, men’s greater risk of dengue infection is found only within those groups that are young and of working-age.

During the recent earthquake in Japan, Iwate prefecture reported that men received mental health and psychosocial support (MHPSS) at disproportionately low levels relative to women. While men in this area may be less likely to request MHPSS, men may also face reduced access to these services. For instance, many working-age men have returned to work during the day and may therefore be unable to access the MHPSS that is provided during the day at evacuation centres. As a result of gender awareness training, ESR staff were able to pick up on this issue, and subsequently explored ways to remedy the situation.

In another example, a possible sex imbalance in the newly documented Severe Fever with Thrombocytopenia Syndrome (SFTS), associated with tick-borne bunya virus infection in China, was also noted by ESR staff. Among SFTS cases (N=241), 56% were female, which differs significantly from the 49% expected female proportion of cases, given the underlying population at risk. Staff noted the importance of the fact that, in the affected rural areas, a large proportion of working men, while legally registered in these rural locations, are actually migrant workers who have relocated to urban settings.

Findings from this type of analysis have important implications for disease prevention and outbreak response. For example, the results of the above dengue analysis may be used by countries to create more specific dengue prevention messages, taking into consideration both age and gender. Moreover, findings from the Division team’s retrospective, quantitative analysis of sex- and age-disaggregated data will be published in the Western Pacific Surveillance and Response (WPSAR) journal.

Staff members’ gender awareness and capacity for gender analysis has increased significantly since the start of gender mainstreaming activities. Furthermore, the 2011 meeting of the Asia Pacific Technical Advisory Group (TAG) on the Asia Pacific Strategy for Emerging Diseases included a session
on gender in EIDs and actions for the future. The incorporation of a specific focus on gender during this crucial yearly planning meeting is representative of the level of support, commitment, and progress made within the Division thus far.

Future plans include pilot testing of a newly developed Division-specific gender analysis tool in Lao People’s Democratic Republic and several other countries. The tool consists of questionnaires to community workers, health care workers, and managers. It assesses gender-specific health care accessibility and health-seeking behavior, so as to better understand representativeness and potential distortions in reported IBS surveillance data.

**Evaluation of Results / Follow-up and Lessons Learned**

While still in the initial stages of incorporating gender analysis as a pivotal aspect of its work, the Division of Health Security and Emergencies of the Western Pacific Regional Office has shown strong commitment, progress, and promising success in its efforts to promote gender awareness among staff, increase sex- and age-disaggregated data collection, and enhance gender analysis of data. Through interactions with gender experts, Division staff have realised the valuable contribution they can make in addressing gender in emerging and infectious diseases (EIDs) through the analysis of previously collected data. A gender analysis tool and a framework for gender analysis in EIDs were developed with the consultation of gender experts. Gender activities were considered and incorporated during the five year work plan under APSED 2010 and have been incorporated into country office guidelines for communication with Ministries of Health and other partners at country level. Sessions focused on gender issues were included in the crucial yearly Technical Advisory Group (TAG) meeting to build further awareness among the Member States and to put gender-aware practices into action under the rubric of APSED 2010.

Following these activities, Division staff began to encourage local and country reporting bodies to report sex- and age-disaggregated data, a strategy that has proven to be successful in increasing the availability of this information. Moreover, Regional Office staff have begun to conduct gender analysis whenever sex-disaggregated data is reported in the IBS. More in-depth retrospective analysis of available data has also been conducted. These activities have raised important gender issues that would not have otherwise been noted or acted upon, such as dengue in various countries or mental
health services in post-earthquake Japan.

At present, it is still not the case that all IBS data are invariably reported with sex- and age-disaggregated information. This is one area for further work in the near future. Additional areas for further work are training in gender awareness and gender mainstreaming practice to new staff who join the Division and to national counterparts, and further extension of the base of knowledge regarding gender norms, gender roles, gendered access to health care, and other disease-related gender issues in the various countries of the Western Pacific Region. Further continued analysis of sex disaggregated data available in ESR and sharing and publishing results of analysis in WPSAR journal, not only benefits ESR programme effectiveness and efficiency, but also contribute to wealth of knowledge on gender and EIDs. The Division staff’s ongoing work in this arena is already making significant progress towards these goals.

The primary lessons learned from this case study are that gender awareness training of staff and staff collective planning are useful avenues by which to begin the process of gender mainstreaming. Additionally, full support from all levels of leadership has been crucial to the success of gender mainstreaming within the Division. In particular, support for gender mainstreaming and pressure to implement gender mainstreaming by Division and Regional Office leadership have been crucial to the early success of these efforts.
Appendix - Gender Analysis Tools Used by the Division

Gender Analysis Matrix for Emerging Infectious Diseases

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<thead>
<tr>
<th></th>
<th>Sex</th>
<th>Gender</th>
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<tbody>
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<td>1</td>
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<tr>
<td>Factors which</td>
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<td>influence disease</td>
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<td>transmission and</td>
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<td>outcome</td>
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<tr>
<td>Biological factors</td>
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<td>Pregnancy</td>
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<td>Norms and behaviour</td>
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<td>Male-female</td>
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<td>division of labour</td>
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<td>Access and control</td>
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<td>over resources</td>
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<tr>
<td>and decisions</td>
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1. Vulnerability
2. Exposure
3. Response to illness
4. Public Health interventions

Gender Analysis Matrix for Emerging Disease Surveillance and Response

<table>
<thead>
<tr>
<th>Factors which influence exposure to the disease, incidence, and mortality</th>
<th>Sex</th>
<th>Gender</th>
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<tbody>
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<td></td>
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<tr>
<td>Biological factors (including pregnancy)</td>
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<td>Sociocultural factors</td>
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<td></td>
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<tr>
<td>Access to and control over resources and decisions</td>
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<tr>
<td>Susceptibility and vulnerability</td>
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<td></td>
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<tr>
<td>Exposure to the pathogen</td>
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<tr>
<td>Risk perception / Information / Communication</td>
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<td></td>
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<tr>
<td>Access to health services</td>
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<tr>
<td>Health-seeking behaviour</td>
<td></td>
<td></td>
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<tr>
<td>Clinical care and case management</td>
<td></td>
<td></td>
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<tr>
<td>Physical, psychological, and social outcomes of illness or disability</td>
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<td></td>
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</tbody>
</table>
Key Questions for Use During or in the Immediate Aftermath of an Acute Public Health Event

1) Is the case data **disaggregated** by:  
- Age  
- Sex  
- Location (including Rural or Urban)  
- Pregnancy Status

If the data is not disaggregated, can we obtain this information at this time or in the near future?

2) What biases or confounders could be affecting the outbreak surveillance data?

3) How has the access to health care or health service utilization of various groups affected any selection biases in the data?

Is any information regarding the health care access and utilization of various groups within the affected population (women, men, girls, boys, elderly, ethnic groups, female-headed households, urban slum dwellers, etc.) accessible at this time (through accessing relevant studies or talking to informed individuals)?

4) Which groups are high-risk in terms of exposure to the infectious agent or hazard?

Which activities bring males and females, males and females of various age groups, or males and females of various ethnic groups into contact with the infectious agent or hazard?

Is any information regarding the division of labour among males and females within the affected population accessible at this time (through talking to informed individuals or accessing relevant reports)?

5) Are public health messages to affected populations likely to reach all vulnerable groups?

Which groups are less likely than others to be reached?

6) Which measures could improve detection, diagnosis, and treatment of groups with poor health care access (or animals on backyard or unregistered farms)?
A DRAFT GENDER TOOL

A tool for consideration of gender for analyzing emerging infectious diseases surveillance data

Introduction

Analysis of data by time, place and person (including sex) is a basic component of descriptive epidemiology and has been a routine practice during outbreak investigations and surveillance information analysis of infectious diseases.

Such analysis provides important information on the possible source or exposure, route of transmission, and specific risk factors for disease. For example, if we find differential disease occurrence between groups that differ by person (e.g. age group, sex, occupation), such finding has important implications for intervention.

Sex is often an important risk factor for disease as there are not only biological differences between men and women but also differential disease risks due to varying risk of exposure, which are often associated with gender roles and norms such as but not limited to occupational practice, jobs, health seeking behaviour, parental roles and many more. One such example would be in the reported human monkey malaria cases in Sarawak, Malaysia where the monkeys carrying the plasmodium knowlesi parasite, infect humans through the mosquito vector. During the clearing of forests, both the husbands and wife are outdoors (daytime) and during night times, usually the wife is asked to sleep in the forest to take care of the crops because the monkeys come to attack the crops, while the husband would go home to take rest before the next day. This predisposes the wife to being bitten by the mosquito infected with monkey malaria. Another example is women who live in the remote areas of Sabah and Sarawak of Malaysia have little or no access to health care. Their husbands on the other hand work outdoors and often would seek medical help from healthcare facility further away.

As such, sex is routinely assessed as a possible risk factor for disease in epidemiologic analyses.

However, there are at least two possible situations where sex- or gender-associated disease risk may not be apparent even if it truly exists.
• Sex-associated differences in disease risk cannot be observed at the aggregate level, and only appear when the data are stratified to finer age groups. For instance, disease risk between men and women may not differ overall, but "depend" on their age, such that there are differences in disease risk between men and women for some age groups but not for others. This is also common epidemiologic knowledge, known as "effect modification" or "interaction". However, this is more for analytic epidemiology, and attention has not been paid so much for looking further into data to look for such phenomena when no notable difference is observed at the aggregate level. While numbers may be small and therefore less reliable under outbreak conditions, such stratified analyses should be possible and conducted for routine indicator-based surveillance data.

• Indicator-based surveillance data are based on routinely collected (passive) data that are reported by health clinics, hospitals, and other healthcare institutions part of the surveillance system. As such data only reflect reported data, they may be limited by selection bias if accessibility to health care or health-seeking behaviour differ between the sexes. Being mindful of gender issues, we should take into account such possible biases that may be in operation in surveillance data. We therefore propose to utilize a gender analysis tool to assess gender-specific health care accessibility and health-seeking behaviour to better understand the representativeness of the reported surveillance data.

Method

1) Age- and sex-disaggregated data collection and reporting of indicator-based surveillance data for prioritized diseases/conditions from Country Offices to assess for differential disease risk by sex.

2) Follow-up analysis of surveillance data by utilizing the newly proposed gender analysis tool. The tool can help assess if the reported surveillance data may be biased by gender-specific healthcare accessibility and/or health-seeking behaviour. The tool will be used when sex-differences are found at the aggregated or disaggregated level to shed light on the true incidence of a disease/condition (e.g. they may be underestimating female cases if women are less likely to have access to healthcare) in order to better target public health interventions. In addition, if selection bias is found to operate in the reported surveillance data, the findings from the tool will be applied to other
diseases/conditions where no sex-difference was found to reassess the true situation (with exception of illnesses such as sexually transmitted illnesses, health care access patterns may be similar across illnesses).

**Step One**

Consult the following documents for background information on the country or area in which the field investigation will occur:

- The latest Country Health Information Profiles, Annual MOH reports, national health statistics reports or other useful references
  
  Look for any information on health care access or health seeking behaviour in your country. If relevant information is listed, it may be useful to refer to the listed citations for more in-depth information. (Note that the relevant information may not always be available.)

- Available research articles on health seeking behaviour and barriers to access to care for men, women, and other groups in your country.
  
  A search of academic databases should result in the relevant articles. With the exception of illnesses such as sexually transmitted illnesses that touch on socially sensitive issues, health care access patterns may be similar across illnesses. Thus, for example, it may be useful to look at an article on the health seeking behaviour of men and women tuberculosis patients, even if tuberculosis is not your primary area of concern.

- Any other reports or documents on health care access barriers or health seeking behaviour for males, females, and other groups in your country. You may be aware of specific reports with relevance to your country.

**Step Two**

Organise and conduct focus group discussions with key informants and community residents. The literature search conducted in Step One may inform the particular location of your investigation, the
composition of focus groups, or any special foci of inquiry. In general, it may be useful to conduct discussions in two main categories:

- Focus group discussions (FGDs) with community residents, both men and women (consider having separate FGD sessions for men and women)
- Focus group discussions (FGDs) with health care workers and health facility managers

A list of guiding questions for FGDs is found below. While the list reflects key points that should be covered during an investigation, it is not necessary to follow the questions exactly. Wording may be changed, and additional questions may be added as necessary. **It is usually necessary to follow answers with further questions to elicit explanation, clarification, and reasons.** Remember to encourage participation from all discussion participants, instead of relying only on a few particularly vocal individuals for answers. An experienced expert may be temporarily brought onto the investigation team in order to facilitate this process.

In particular, the team should look for and take note of patterns of difference between men and women, especially those arising from cultural or gender norms, with respect to the issues raised in the list of questions below.

**Questions for FGDs with Community Residents**

1) What health problems have you and your family members faced?
2) Where do you first go for care, medicine, or treatment when you are sick?
   - If the first treatment attempt does not succeed in reducing illness, what do you then do?
3) How long do you usually wait after feeling ill to seek treatment or care?
   - What barriers prevent you from seeking care earlier?
4) What, if anything, is likely to prevent you from obtaining health care?
   (Possible answers might include women’s need to obtain others’ permission to use household finances or means of transport, women’s lack of time due to seasonal farming activities or household responsibilities, cultural notions about the need or lack of need for health care, perceived lack of responsiveness of health provider, lack of privacy or confidentiality at the health care facility, etc.)
5) How do families respond when a boy gets sick?
6) How do families respond when a girl gets sick?
7) Are any household members less likely to seek health care than others? Why?
   (Possible answers might include the elderly or women)

Questions for FGDs with Health Care Workers or Health Facility Managers

1) What health problems are commonly seen in this area or in your health facility? Do they vary between men and women?
2) How do local residents become aware of your services? Are men or women more (or less) likely to know about and use these services?
3) What are some barriers to accessing your services that residents face? Do these differ for men and women?
4) What is the sex and ethnic composition of individuals most likely to visit your health facility? Does this distribution adequately or fully represent the composition of the population, or are some groups more likely or able to access services than others? Why or why not?
5) What are some gender roles and norms that are relevant for the health of the population served by this health care facility?

Additional notes on focus group discussions:

The composition of focus groups will vary according to logistical and other constraints. However, in many settings, women may be able to talk more freely in an all-women’s setting than in the presence of men. Similarly, health care workers may be more vocal when among a group of colleagues of equal status than among a mixed group including bosses and managers. Thus, it may be wise to hold separate discussions with a group of women, a group of men, a group of health care workers, and a group of health facility managers.

Focus groups may be composed of “natural” groups within society, such as colleagues or those forming an association or volunteer group. Focus groups may also be composed of individuals who are similar to each other but do not interact in any established group setting. Thus, residents of a given area may be brought together for a focus group discussion, even though these residents may not all know each other. It is best to include a wide range of ages within the community resident focus groups, so as to understand the opinions of different types of individuals. Additionally, if people from ethnic minority groups are significantly represented within the population of the area you are
investigating, a representation of these minorities within the focus groups should be ensured.

Please note additional key informants, such as village leaders or researchers, may be useful to include within focus groups. Separate FGDs with groups that are suspected to have particularly low access to health care may also be desired. Such groups might include people from ethnic minority groups, the disabled, the elderly, widowed females, etc. For simplicity, however, four focus groups are listed here, namely women, men, health care workers, and health facility managers. If time and resources are constrained, FGDs with only some of these four groups may be conducted. Each investigation team will be aware of local information needs and capacities, and can therefore make decisions regarding details of the investigation accordingly.

While this document has been developed to seek gender differences in infectious disease, the principles remain the same for equity related issues such as ethnic differences, geographic difference etc.

References


www.who.int/social_determinants/