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Ethics and Confidentiality

Ladies and gentlemen / colleagues, good afternoon.

My presentation looks at ‘**ethics and confidentiality**’. I suppose that intuitively we all have a general idea of what we mean by ‘**ethics**’ and what we mean by ‘**confidential**’. Nevertheless just to ensure we are all ‘on the same page’ I will start with some basic definitions.

Definitions

The Concise Oxford Dictionary - 10th Edition defines **ethics** as:

1. Moral principles governing or influencing conduct.
2. The branch of knowledge concerned with moral principles.

An alternative definition found in **Collier’s Dictionary** describes **ethics** as:

1. Branch of philosophy that deals with the pursuit of the good, the meaning and justification of moral codes, and the criteria for evaluating right and wrong.
2. Standards of conduct or code of behaviour, as of a profession.

Concise Oxford Dictionary - 10th Edition defines **confidential** as:

1. Intended to be kept secret
2. Entrusted with private information

From this we get the derivatives – confidentiality (noun), confidentially (adv.).

Collier's Dictionary describes confidential as:

1. Originated or maintained in strict secrecy or privacy: confidential files.
2. Indicating intimacy or readiness to disclose matters of a secret nature: a confidential tone.
3. Entrusted with secret or private matters.

In this regard, the **American Statistical Association Committee on Privacy and Confidentiality** - Terms and Definitions expands further. It refers to Confidentiality as a broad concept that may be defined differently depending on the context. Accordingly two definitions are offered to users.

For example one definition quotes, **Private lives and Public Policies**, Washington D.C., which states that, "Confidential should mean that dissemination of data in a manner that would allow public identification of the respondent or would in any way be harmful to him is prohibited and that the data are immune from legal process", the definition observes further that confidentiality is not restricted to data on individuals and is often extended to data on organizations.

The other definition quotes the **IRB Guidebook, Part 111. D, Department of Health and Human Services, Office for Human Research Protections**, which states that "Confidentiality pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission."

"Ethics and Confidentiality" applied to a Statistical Agency

I believe that these definitions should give us some sense of where we are focusing our discussion.

Now, on the surface after having gone through the definitions, it may appear as if there is hardly any need for much discussion, however, when we move from the general to the specific some grey areas may perhaps emerge.

In this instance we will focus on the application to a statistical agency, in particular an official statistical agency. I wish to start by looking at the mandate of such an agency.

To examine the function of such an agency, I will use the example with which I am most familiar, the Barbados Statistical Service.

The Barbados Statistical Service was established in 1956 and is required by the *Statistics Act CAP 192* to perform the following functions:

- To take any census in the island,
- To collect, compile, analyse, abstract and publish statistical information relating to the social, agricultural, mining, commercial , industrial and general activities and condition of the inhabitants of the island (country),
- To collaborate with departments of government in the collection, compilation, analysis and publication of statistical records of administrations and departments; and
- Generally to organize a co-ordinated scheme of social and economic statistics relating to this island (country).

I believe that in general these functions are similar in most statistical departments, agencies or units especially within the region.

What is the relevance of “ethics and confidentiality” to producers of Statistics?

So what is the relevance of ‘ethics’ and ‘confidentiality’ especially to producers of official statistics and is there a link between the two?

William Seltzer in an article entitled “*U.S. Federal Statistics and Statistical Ethics: The Role of the American Statistical Association’s Ethical Guidelines for Statistical Practice*”, addressed the question, “Why do we need to talk about ethics?” And in particular, “why do government statisticians need to talk about and be aware of ethics?” He observed that “there are laws and executive orders to guide us, instructions from supervisors, and the imperatives of science attributable to the field of statistics or to one or another subject matter areas related to specific fields of application”.

Seltzer proceeded to answer the question by pointing out that “unfortunately, these different sources of guidance are sometimes in conflict with each other”. He continued with the observation that the opportunities for conflict multiply when one tries to take into account other important influences of one’s functioning as an official statistician user requests, the policy concerns of elected officials, and one’s personal tastes, preferences and values”.

The writer also observes that “intentionally or not, the actions of government statisticians can lead to a variety of harms”. Further he states that “Ethical norms add another dimension to thinking about our actions as statisticians”. In addition, he adds that they can provide guidance in the process of weighing and sorting through conflicting demands in ways that avoid or minimize the potential for harm”.

Another issue raised was the argument by some against ethical codes or standards on the grounds that it is enough for us to be good statisticians scientifically and obey the law.

Seltzer warns that those advancing this position are on questionable ground. He pointed out that “the view that moral issues play no role in science and Governmental operations was one of the defenses unsuccessfully offered by those found guilty of war crimes and crimes against humanity at the Nuremberg War Crimes Tribunals for planning and carrying out medical experiments on concentration camp inmates during World War II”.

What are the main Issues?

Clearly the examination of these issues is of course not new and if by now we are convinced that there is merit in the application of ethics and confidentiality we can then turn our attention to the question of what are some of the main ethical issues we should be considering.

Once again in another article entitled “*Official Statistics and Statistical Ethics: Selected Issues*”, **William Seltzer** (2) provides some interesting pointers which can perhaps be used as guidelines. He identifies what he deems to be the main ethical challenges that arise in official statistics. They are as follows:

- (a) Use of sound methodology
- (b) Protection of confidentiality
- (c) Integrity of the statistical agencies and the national statistical system.

Perhaps then we may wish to look at these issues identified above in more detail.

- (a) **Use of sound methodology:** Seltzer makes the case that ‘the failure to use sound technical methods can be so flagrant or long-standing as to present serious ethical issues’. He posits that ‘in official statistics, this sort of situation may arise when a seriously flawed or outdated methodology

continues to be used by an agency long after its shortcomings have been identified and alternatives approaches explored, but for inappropriate reasons (for example, political pressures or a false sense of institutional pride), the flawed approach remains in use, sometimes for decades’.

With regard to us regional practitioners, this reference to methodologies will no doubt remind us that methodologies are not cast in concrete, but rather requires a constant review and renewal where necessary and possible. The trust that users have in the data we produce should make us aware of importance of the exercising of responsibility to be professional.

- (b) **Protection of confidentiality:** In an interesting observation, Seltzer refers to the roots of the concept of statistical confidentiality and the protection from harm, attributable to cooperating with statistical enquiries as traceable back to the ‘Hippocratic Oath’ where physicians agree not to cause harm to their patients and not to gossip about information obtained in the course of their professional work.

With respect to the Caribbean region, I daresay most if not all the statistical agencies operate under an act which provides for the taking of censuses and for the collection, compilation, analysis and publication of statistical information. These acts generally provide restriction of publication of any information which would identify an individual householder or business. Significantly, the *Barbados Act* provides for restriction on identification of costs of production, or profits arising, in any such undertaking or business.

We should note however that while adherence to confidentiality provisions is laudable, it may create a barrier to attempts to fulfill some important responsibilities. For example, the Barbados Statistical Service has a responsibility for the Collection of Damage Assessment Statistics in the aftermath of hazard impact. Such an event creates the need for information on individuals who may be impacted as a result of a disaster event. The dilemma however is that the need for that kind of individual data runs into the face of the provision for maintaining confidentiality as outlined in *the Statistics Act CAP 192* which stipulates that data should not be provided in any way which would identify an individual or company/or other institution.

Other instances may occur when looking at poverty where the quite noble aim of providing assistance to the person or persons in need may run counter to the requirement to protect the confidentiality of the individual.

The observation made earlier about context being a determining factor related to the definition of confidentiality is relevant. The same may be true with regard to organizations with different functions operating under different guidelines. There are some things for instance that the media may highlight but the statistical agency cannot, e.g. information on an individual person or business may be highlighted for very noble reasons such as drawing attention to the plight of an individual in poverty stricken circumstances or of the difficulties caused by circumstances of whatever nature. The statistical agency would be constrained by its *Statistic Act* from supplying information to users in that kind of detail.

We can see then that the issue of confidentiality is certainly a factor for statistical agencies in small states and may even at times be an internal issue. Certainly situations can arise even within the confines of the statistical agency. For example, the phenomenon of AIDS and the compilation of HIV/AIDS infection data and more particularly statistics of deaths as a result of HIV/AIDS can provide opportunities for those who have special skills grounded in mischief making and rumour-mongering. Much care should be taken to ensure that even persons working in institution which provide official statistics, and who therefore have access to confidential information, but who do not work in that area may misuse that privilege, e.g. perusing cause of death forms. Small communities provide for a more intimate knowledge of individuals. Personal information on a neighbour, relative or acquaintance also needs to be protected.

(c) Integrity of the statistical agencies and the national statistical system:

Seltzer points to an important focus of the Fundamental Principles of Official Statistics as the maintenance and enhancement of the integrity of the national statistical system.

Among the examples of the threats to integrity as including, arbitrary political manipulation of concepts, definitions, and the extent and timing of the release of data, doctoring the actual data released, using the agency for political analysis or other political work, and politicizing agency technical staff.

We ought also to be aware that the integrity of a statistical agency and system can be called into question, even when there is no breach of confidentiality with regard to individual data whether on persons or organizations. Such questions can occur even when providing aggregate data.

Hermann Habermann, (*whom I presume to be the same person listed as a participant at this conference*) in an article on '*Ethics, Confidentiality and Data Dissemination*' writes of recent concern about data provided by the U.S. Census Bureau to the Office of Customs and Border Protection which is part of the U.S

Department of Homeland Security. It appears that aggregate information was supplied on the Arab-American community in 2002 and 2003 as requested by the office and supplied by the U.S census Bureau.

What is significant is that the data was **not** individual data and did not violate any provision for confidentiality. Furthermore, the data were already publicly available on the US Bureau's website. Nevertheless, concerns were raised by civil liberties groups and Arab-American advocacy organizations who while conceding that the assistance was legal, nevertheless described it as a dangerous breach of public trust. Comparisons were drawn with a previous occasion when the U.S Bureau supplied similar information on the Japanese Community to the Japanese War Relocation Program during World War II.

Conclusion

The work of statisticians and related personnel who are involved in the collection, compilation, analysis and dissemination of statistical data, requires them to deal with ethical issues as well as the confidentiality factor relating the whole process of data production as well as challenge of the dissemination of data.

The challenge is to satisfy the needs of users on the one hand, while at the same time paying attention to ensuring that the data we supply stays within the boundaries of ethical behaviour and paying regard to the need for confidentiality. However, we are also reminded or alerted that it is not always easy to do, to strike a balance between these sometimes contrasting requirements.

The information presented was intended to remind data producers in some cases and in other cases make some aware of the awesome responsibility we have with regard to the production and dissemination of statistical data. It is hoped that the discussion of these important issues will be of benefit to all involved in the process of statistical data production and dissemination.

REFERENCES:

- (1) **William Seltzer**, *U.S. Federal Statistics and Statistical Ethics: The role of the American Statistical Association's Ethical Guidelines for Statistical Practice*.
- (2) **William Seltzer**, *Official Statistics and Statistical Ethics: Selected Issues*.
- (3) **Hermann Habermann**, *Ethic, Confidentiality and Data Dissemination*.