# Participating in and using the Global Burn Registry - Frequently Asked Questions

Please find answers below to the following frequently asked questions about the Global Burn Registry (GBR):

- 1. What are the main steps in participating in and using the GBR?
- 2. Is it difficult to complete the data collection form?
- 3. Is the GBR available in a number of different languages?
- 4. How does one register a health facility to participate in the GBR?
- 5. Are there conditions that must be accepted for a health facility to participate in the GBR?
- 6. What is the difference between the "public view" and the "private view" of the GBR?
- 7. What types of data are available within the public and private views of the GBR?
- 8. Is ethical approval necessary for a health facility to participate in the GBR?
- 9. Is ethical approval necessary for a research undertaking that will make use of data contained within the GBR?
- 10. Where are the data uploaded to the GBR stored?

#### 1. What are the main steps in participating in and using the GBR?

A focal person registers a health facility to participate. WHO reviews the registration and then sends a participation agreement which must be signed on behalf of the health facility. Upon receipt of the signed participation agreement and approval of the registration, WHO sends electronic documentation to the focal person. The documentation sent includes the data collection form and a guidance document, as well as information on uploading and accessing data. The data collection form should be printed out and completed by clinical staff treating a burn patient – one form per patient. After the patient has been discharged, staff within the health facility should upload the information from the data collection form to the GBR.

### 2. Is it difficult to complete the data collection form?

No. Pilot testing in over 30 countries shows that it only takes approximately 5 minutes to fill in the form. Most of the form uses check boxes, so there is very little writing involved. The form is designed to be used only on inpatients, defined as those admitted to a health facility for treatment of a burn injury. It is not meant to be used for outpatients. Since most patients admitted for burns are in a health facility for days or weeks there is ample time to fill in the form and it does not interfere with the provision of emergency care.

#### 3. Is the GBR available in a number of different languages?

The data collection form is available in English, French and Spanish. The guidance document is available in English. The GBR online interface, which allows one to view and access data, is available in English, French and Spanish.

### 4. How does one register a health facility to participate in the GBR?

There is a link at the bottom of this page which allows one to register one's health facility to participate in the GBR. Before clicking that link it is recommended that one first reads through the remaining questions and answers on this page.

### 5. Are there conditions that must be accepted for a health facility to participate in the GBR?

Participation in the GBR requires acceptance of a number of conditions. These are provided in the participation agreement to be signed by the health facility prior to participation in the GBR. Registering a health facility to participate in the GBR acknowledges acceptance of these conditions.

## 6. What is the difference between the "public view" and the "private view" of the GBR?

WHO provides a public view and a private view of the GBR data. The public view can be seen by anyone, and provides information from all participating health facilities. In order to ensure confidentiality, WHO has undertaken to ensure that some GBR information is either modified or not provided within the public view. The private view is available only to participating health facilities. It provides access to all data from a given health facility to that health facility only. The link below provides a detailed overview of the information available in the public and private views of the GBR and shows similarities and differences between the two.

• Click here to see the detailed differences in data available with the GBR between the public and private views

### 7. What types of data are available within the public and private views of the GBR?

The public and private views of the GBR make information available that covers the following broad areas: health facility information; non-identifying patient information; burn and burn treatment information; and cause of burn information. As stated in FAQ 6, some information is either modified or not provided in the public view. For a detailed description of the differences of data elements available in the public and private views please click the link below FAQ 6 above.

#### 8. Is ethical approval necessary for a health facility to participate in the GBR?

Health facilities are required to confirm, as part of their participation agreement, that they have obtained any ethical approvals their health facility may deem necessary for them to participate in the GBR. While WHO cannot, and does not, provide input on the particular ethical rules or requirements applicable to any health facility, it is WHO's understanding that as a general matter ethical approval for human subjects research or otherwise would not be necessary for a health facility to register and participate in the GBR. This is because the GBR standardizes data collection on burns and is therefore not itself, in WHO's view, a research undertaking but rather an effort to improve and standardize a form of surveillance. The GBR, and the manner in which data of the GBR are made publicly available, have had ethical review conducted by the WHO Public Health Consultative Group, an internal WHO advisory body.

# 9. Is ethical approval necessary for a research undertaking that will make use of GBR data available in the public view?

While WHO cannot, and does not, opine on the particular ethical rules or requirements applicable to any undertaking or research project, it is WHO's understanding that ethical approval would not be necessary for research projects, as the GBR data available in the public view do not make individually identifiable data publicly available. Nevertheless, all

researchers must consider whether a specific research undertaking requires ethics approval, and, as provided in the terms of use for the GBR, are solely responsible to ensure that they have obtained all ethical approvals necessary for their proposed use of the GBR information.

### 10. Where are the data uploaded to the GBR stored?

Data that are uploaded to the GBR are stored on network servers that are physically located on the premises of WHO at its headquarters in Geneva. WHO has implemented many levels of security using industry best practices for the local WHO network and all databases maintained by the WHO. These security practices are constantly evolving as industry standards regarding information technology security change. All WHO databases are backed up often. Notwithstanding the foregoing, as provided for in the terms of use, WHO makes no guarantee to the security of the data, or to make the data available through the GBR, which WHO may cease at any time.

- Click here to register your health facility to participate in the Global Burn Registry
- Click here to see the Terms and Conditions of Use for the GBR data and to access the GBR data