WHO Clinical Registry – Frequently Asked Questions

1. What is the purpose of a clinical registry?
   A clinical registry is a comprehensive database that houses detailed information about patients with specific conditions or receiving specific interventions. Registries enable monitoring and tracking of treatment outcomes, facilitate quality improvement initiatives by identifying areas of patient care for intervention, and provide valuable data for research purposes. Registry data contribute to evidence-based medicine by offering real-world insights into treatment effectiveness and guiding clinical decision-making. Clinical registries may also serve regulatory purposes, aiding healthcare organizations in compliance with standards and reporting requirements. Overall, clinical registries play a pivotal role in advancing medical knowledge, improving patient care, and informing healthcare policy and practice.

2. Where would I use the WHO Clinical Registry? For what type of patients would I use the registry?
   The WHO Clinical Registry is intended for use in a range of clinical settings in primary care or in hospitals. Current modules assist in the case-based analysis of trauma and medical emergencies for quality improvement, but critical care and operative case management modules are under development.

3. How is the WHO Clinical Registry connected with IRTEC (the International Registry for Trauma and Emergency Care)?
   IRTEC has been renamed as the WHO Clinical Registry.

4. How do I join the WHO Clinical Registry?
   First, fill out the registration form. The WHO team will reach out to you via email with materials on the WHO Clinical Registry. Upon reviewing the materials and determining the suitability for your needs, you can respond to the email to confirm. Please ensure to attach the signed WHO Clinical Registry Standard User Agreement endorsed and signed by your facility administrator.

5. How will I get access to the WHO Clinical Registry?
   Once you have sent the signed user agreement, we will send you a blank user template. Kindly complete the template with the details of the facility users, including names and administrative hierarchy, so that we can incorporate them into the registry platform.

6. Is there a subscription fee to join?
   No, there is no subscription fee as WHO covers the maintenance costs of the platform itself. However, it is important to note that there may be implementation costs at the facility or country level, such as hiring data collectors or internet subscription cost.

7. Is there training to use WHO Clinical Registry?
   Yes, the WHO registry team will provide online training. Along with the training sessions, we will provide you with comprehensive training materials, allowing you to conduct self-paced training sessions. This approach ensures that you benefit from our guided online training and have the freedom to delve deeper into the training materials, allowing for a more thorough understanding and mastery of the content.
8. Do we need a device to use the WHO Clinical Registry?
   To access the registry platform, you will need either a desktop/laptop or an Android device. When using a laptop or desktop, you can access the WHO Clinical Registry platform through a web browser (Google Chrome is recommended). Alternatively, if you are using a mobile device, you may download the free mobile app from the Android PlayStore to access and enter data into the platform.

9. Do we need an internet connection to use the WHO Clinical Registry?
   An internet connection is required when using a desktop or laptop to log in and access the WHO Clinical Registry. The Android app supports offline data entry, enabling you to synchronize the data once a stable internet connection is available.

10. Will other facility users be able to see our case-based data?
    No, access to case-based data is restricted to users within their respective facilities. This means that users are only able to view and interact with data from their own facility. This approach ensures data privacy and security while maintaining confidentiality and integrity across all facilities utilizing the platform.

11. Who is the ‘data owner’ of the case-based data we enter into the WHO Clinical Registry?
    The data owner of the case-based data is your facility. This is stated clearly in the Standard User Agreement that will be signed by your facility administrator prior to commencing data collection.

12. Who maintains the WHO Clinical Registry platform?
    The WHO maintains the WHO Clinical Registry platform. The server is physically located in headquarters in Geneva but, as mentioned above, the data ownership stays with the facility.

13. Are we required to use the WHO Standardized Clinical Forms in order to use the WHO Clinical Registry?
    If your facility does not have an established clinical form in use, we recommend adopting the WHO Standardized Clinical Form. This form facilitates systematic care delivery for each patient and ensures consistent data collection, supporting quality improvement efforts and system planning. Alternatively, if you already have a functioning clinical form and prefer to continue using it, we can assist in aligning the necessary variables for data collection with the WHO Clinical Registry standards.

14. What are the enablers to a successful implementation of the Clinical Registry?
    One of the enablers to a successful registry implementation is having a local champion; a committed and enthusiastic clinical team who understand quality improvement principles and are motivated to improve care is also key. Having someone leading the way and a team that's ready and motivated to enhance the quality of care in their setting play a key role in driving the registry implementation to success.

15. How many data inputters are required to enter data?
    The number of data inputters required will vary based on the patient volume within your facility. The larger the number of patients, the more data inputters may be necessary to ensure a timely and accurate entry of information into the system. The size and complexity of your facility, as well as the frequency of admissions, will also influence the staffing needs for data inputting.