



WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

## QUALITY DATA COLLECTION

### Why collect data?

Data collected nationally by World Federation of Hemophilia (WFH) members are extremely useful in advocating for better care for people with bleeding disorders. It can be used at the national level and also compiled globally by the WFH. Data have demonstrated the effectiveness of starting national programs and providing even small amounts of safe clotting factor concentrates in improving health outcomes. It can also be used to support the continued provision of existing levels of care (for example, demonstrating value for cost or long-term savings), focusing targeted outreach, and guiding decisions about where to allocate limited resources.

Data quality is about reliability. When you know that you have high quality up-to-date data, you can confidently use it for effective advocacy, meaningful research, relevant strategic planning, and the management of health care delivery.

### Criteria for quality data

To ensure that the quality of the data you collect is high and that you can confidently use them, check whether the data meet the following criteria:

- **Relevance and completeness** – data include all (and only) those items required to answer the chosen question. For example, to be able to reach conclusions, a study of the effectiveness of prophylaxis requires data on when treatment was started, its intensity, the proportion of prescribed doses actually administered, and joint function or quality of life assessment results.
- **Reliability** – as much as possible, data reflect the real situation; in some cases approximation, but not guessing, may be acceptable. The impact of different settings and treatments or changes over time can only be measured if precise data is used. For example, if a patient registry does not take into account death or emigration, this could lead to an overestimation of the real patient population and incorrect conclusions about the amount of factor used per patient.
- **Timeliness and understandability** – data must be collected with a speed (one-time surveys) or frequency (ongoing data collections, such as registries) that fits the intended use; and using standard technical terminology. Also important, it must be reported in language that is clear to the intended users.



## How to collect quality data

Data can be collected at the level of the community (number of patients, cost per unit of factor, total amount of factor used, number of patients on prophylaxis, healthcare system organization) or collected at the level of the individual (number of bleeds, severity of pain, number of school or work days missed). Data collected at the individual level should be collected for many individuals and then averaged – to demonstrate real trends rather than just anecdotal evidence.

As a first step, clearly define the question to be answered and ensure that the data collected are appropriate for that purpose. When possible, use validated tools to collect data. Validated tools are methods for collecting data that have been assessed and found to be reliable. Try to measure simple, objective, quantifiable characteristics or events, rather than complex or subjective ones (for example, number of school days missed rather than level of education). Measurement methods should be reproducible, so as to give similar results if used again at some other time, or by someone else, to measure the same phenomenon.

Consult peers, published studies, or the WFH for advice on data collection strategies and tools.

## Keys to successful quality data collection

- Obtaining endorsement and support from leadership and stakeholders (health ministries, treatment centres, clinicians and patients), in the form of shared vision and mission, organization-wide policies, and resources for implementation.
- Providing adequate training and support for data collectors.
- Planning quality check processes, and distributing reports of the collected data, so that it serves a real purpose.

## References

1. WFH Compendium of Assessment Tools: [www.wfh.org/assessment\\_tools](http://www.wfh.org/assessment_tools)
2. *What you should know about Data Quality – A guide for health and social care staff*. Published by The Health Information and Quality Authority. 2012. <http://www.hiqa.ie/publications/what-you-should-know-about-data-quality-guide-health-and-social-care-staff>
3. *Guiding Principles for National Health and Social Care Data Collections*. Published by The Health Information and Quality Authority. 2013. <http://www.hiqa.ie/publications/guiding-principles-national-health-and-social-care-data-collections>