

7th Global Patients Congress

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PATIENT INVOLVEMENT IN STANDARDIZATION OF TERMINOLOGY AND DEFINITIONS AND GUIDELINES

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bird's eye view....



- **Guidelines** are recommended methods for diagnosis and treatment, and usually include algorithms. But they may also include changes in terminology and definitions. An important objective of guidelines is to reduce risks/improve safety for the patient.
- **Pathways** are a care plan, often called integrated care pathways, or clinical pathways; while the term protocol is often used in the USA.
- **Taxonomy** is a classification method, for example the IASP pain taxonomy, which provides standard descriptions as well as standard terminology.
- **Standard/Standardization:** Once adopted, a standardization document on a specific topic or area is known as a Standard.

Impact on the patient...

- In today's world, healthcare is a chain with multiple links and standardization can have an impact on every link in the chain.
- many of these links directly affect the patient;
- standardisation can therefore have a major impact on the patient, the patient's healthcare and indeed ultimately the patient's whole family.



Impact of terminology/definitions on the patient

Terminology and definitions have:

- a research impact, ultimately affecting the patient
- a medical impact on the patient
- a social/financial impact on the patient

Research Impact

If the terminology and definitions are not right, research will go down the **wrong** pathways, reach **wrong** conclusions, thereby ultimately leading to **wrong** treatment and **exclusion** of important groups of patients.



Medical Impact

Right terminology and definitions mean:

- ✓ **Right** diagnosis
- ✓ **Right** treatment and **Access** to treatment
- ✓ **Improved** quality of life for the patient

Social and Financial Impact

Official recognition of the condition means eligibility to receive:

- Reimbursement of treatment
- Unemployment benefits
- Disability benefits
- Social services and care



Official recognition

Official recognition of a condition is vitally important in today's complex electronic healthcare world where so many different authorities have a finger in the healthcare pie and each may have its own electronic coding system.

Patient input in standardisation process: why?

Reasons include:

- Terminology and definitions should correspond to the disease or complaint as experienced by the patient.
- Square patients should not be forced into round holes to fit in with some researcher's pet theory.
- Terminology and definitions should cover the full spectrum of a disease or complaint with all its variations.
- No groups of patients should be excluded.

Patient input

Patient organizations can provide standardization committees with supplementary information and insight, helping to create a comprehensive picture of each condition and everything this involves along the entire healthcare chain.

References

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Thank you!