PATIENT INVOLVEMENT IN THE DEVELOPMENT AND SAFE USE OF MEDICINES

Personal views

François Houÿez

PCWP-HCPWP joint meeting , 3-4 March 2020

Beyond technical aspects (on how to involve us), it is all about politics| our role in society

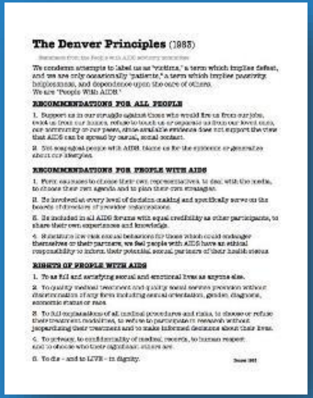
And how principles are applied

The Denver principles of patient advocacy

1983

Denver, 9-12 June 1983 – LGBT conference

We condemn attempts to label us as 'victims,' which implies defeat, and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence upon the care of others. We are 'people with AIDS'.


The Denver Principles (1983)

RECOMMENDATIONS FOR ALL PEOPLE

RECOMMENDATIONS FOR PEOPLE WITH AIDS

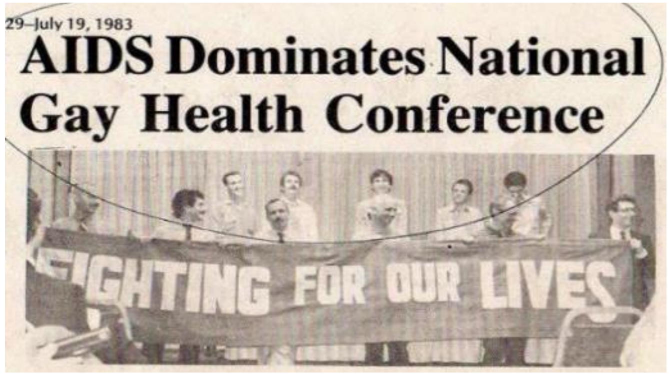
RIGHTS OF PEOPLE WITH AIDS

http://www.actupny.org/documents/Denver.html

To form caucuses to choose your own representatives, to deal with the media, to choose your own agenda and to plan your own strategies

To be involved at every level of decision-making

To be included in all forums with equal credibility as other participants, to share their own experiences and knowledge


29–July 19, 1983

AIDS Dominates National Gay Health Conference

Chapter 3: Guiding Principles for Patient Engagement

1. **The patient voice offers a relevant perspective throughout the medicine lifecycle and should be incorporated in such a way to produce meaningful value.**

    a) Patient representatives and patient organizations are relevant intermediates to enable that the patient voice to be incorporated as feasible throughout the medicine life cycle

    b) Every patient engagement activity should have clear goal(s), and designed in such a way to achieve those goals

        i. Those who engage patients should have clear goals or questions that they are seeking to answer. This includes communicating these goals to patient representatives and patient organizations, to help them evaluate whether they should participate.

Should be symetrical: those who engage with patients should be ready to respond their questions, consider their priorities, respect their agendas, listen to their expectations.

Chapter 3: Guiding Principles for Patient Engagement

c. To help ensure that patient engagement produces meaningful value, when planning a patient engagement activity considerations should be given to:

   i. Representativeness and diversity and inclusiveness (irrespective of age, race, gender, domicile and socio-economic status) not elitist

   ii. How to select patient representatives / patient organizations to work with, consideration given to what expertise and experience is needed for effective participation

   iii. Consideration for special patient populations

This gives the impression only third parties decides on practical aspects of engagement.
Patients' organisations have their own structures, they can decide who they want to work with, how (e.g. Community Advisory boards) and with their own rules (composition, training, diversity…)

A constant need to

Be vigilant on how principles are applied by third parties

Patients' organisations can define their own rules

No complaisance: willingness to comply with third parties' rules can put some principles aside

"Principles", "Eligibility criteria" should always be co-defined – concepts of Soft Justice, Deliberative Democracy and "Health Democracy"

Thank you for your attention.

François Houÿez

Director of Treatment Information and Access

francois.houyez@eurordis.org