1) In which way involved

Involvement in several ways.

- By the patients advisory board on general issue's
- By interviews on specific topics
- Special representative within the Board of CBG/MEB

Impact difficult to measure.

Have the feeling we are listened to and their is a genuine interest on patients point of view. However there is a restriction of what can be done regarding legal rules / requirements

Strength and weakness.

The strength is that the patients can and are involved in any way possible. The weakness is the regulations which prohibits the patients to play a more active roll in the final decision making process. There were it comes down to what is the impact on the quality of life and how is that been judged.

2) general discussion on patients involvement

Granting access to medication.
Within the Dutch system there are more players active in granting access to medication.
First
EMA marketing authorisation. Almost non involvement of the national patient advisory board on that process.
National marketing authorisation non to a little involvement as the scientific criteria are set on forehand (not discussed with patients representatives)
Second
NZA (National Healthcare Authority)
Regardless any marketing authorisation they set the boundaries for healthcare professionals if they may prescribe he medication, if they will be reimbursed (price setting) or if there is a preferential medication. Involvement of patients associations is limited.

Topic has been put on the agenda a couple of times and changes have been made although scientific criteria still are not discussable and quality of life criteria are not developed.

Joop van Griensven