

Decentralised clinical trials from a patient perspective

Hans Scheurer MSc

Myeloma Patients Europe (president 2016-2022)

WECAN network EU cancerpatientcommunities (chair 2022-2023, vice-chair 2023-2024)

Disclosures

- No COI's to report related to this session topic

Questions

Decentralising trials

- Budget driven, or driven by patients unmet needs?
- What are the changes for patients?
- Keys to make it work with patients
- Take home messages

Drivers for decentralisation

- Patient unmet need or budget driven? A bit of both
 - Limiting travel to and stay at hospital
 - Fits in the trend of more responsibility for own care / health
 - We live longer, more elderly, more chronic disease management, overall more use of healthcare; the price of success
 - Fast innovative development in healthcare; access under pressure
 - Unequal access to innovation: is decentralisation a part of the solution?
 - Fast development solutions in information technology for healthcare make treatment, healthmonitoring and care in more situations at home possible



What changes for patients?

- Own place, own time
- No travelling
- Responsibility transfer from hospital to patient
- Home devices
- Patient instruction, training
- Support system: when something happens...
- Integration with medical system in use



Keys to make it work

- Make it meaningful for patients
- Patientfriendly information, instruction, training, support
- Flawless system, easy to use, no errors
- Trustworthy system, technical, use of data, data sharing
- Integrated in medical system around the patient
- Feedback, compare with similar others. Can it be fun?
- Adequate support system, alert system, patient adherence



Two take home messages

- Design it with the patient experience in mind....
 - Most patients are positive, unless...
 - Give patients a choice
 - Make the patient experience positive and meaningful
- You only get that broader recruitment, more access, better data, lower pressure on the budget of healthcare when you make it really a positive and meaningful experience for patients.

