A rheumatology patientpanel
The patient is the expert, we are the specialists

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disclosures

• none
Rheumatology-Maasstad Hospital

• General hospital for top-clinical care
• Biggest rheumatology clinic in the region
• Multidisciplinary team
• Shared decision about best treatment
Value Based Health Care

• Optimize the current Healthcare system

• Measure the value for patients: ask them
The patient is the expert, we are the specialists

• Cooperation
• Participation
• Co design new Healthcare strategies
Patient participation

- Education
- Coproduce
- Research
- (Co) decide
- Patient participation
- advice
- Care
- consult
- inform
- inform
How to create a panel

• Staff members asked to nominate patients
• On going process: patients ask patients

Patient Information Form signed
Disclosures
Our panel

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Patients (N)</td>
<td>61</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>17</td>
</tr>
<tr>
<td>Ages (YRS)</td>
<td>51 (20-77)</td>
</tr>
<tr>
<td>Disease duration (YRS)</td>
<td>9 (0-30)</td>
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Patient meetings and subjects:

• Goals and Value for patients
• Evaluate a PROMs measurement tool
• Development and evaluation of a patientportal
• Changing to biosimilar medication
Focus groups on value and goals

• Questions:
  – Which outcomes are important to you?
  – Start phase/ chronic phase
  – What do you need?
  – How do you find that the value of care can best be measured?
What is value for a patient?

- Can you give it a number like on a VAS?
- Is it a feeling, satisfaction, being taken seriously, being able to make decisions
- Able to function (in social life)
Items with value for patients

- Pain
- Communication with healthcare providers
- Need for information
- Satisfaction
Conclusion

• Co-creating innovations along research
• Connect changes to patient perception
• Involving patients as an expert

I’m happy to do something in return for the good care I receive

I want to promote participation in scientific research, it brought me so much
Nurses role:

• Tomorrow: 28th aug 16:00 at Ruys Zaal
• Shared decision making in practice and needs of rheumatic patients on nursing support
Thank you