



Workshop Patient Education:

EUPATI Toolbox

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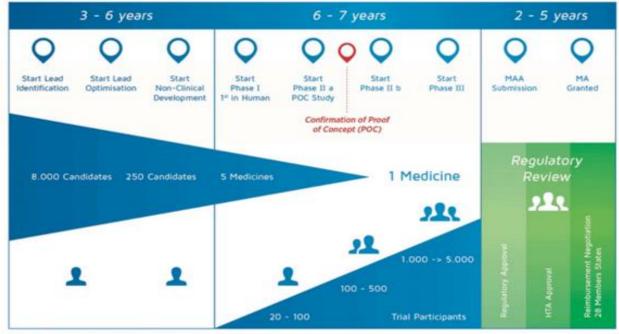
The medicine journey



Overview of Decision Points and Development Steps in Medicines R&D



Framework



Variation Termination of Market Supply

New therapies don't reach patients until this point

Research & Discovery Non-clinical Development Clinical Development Phase I , II & III Post-approval Life-cycle management & Pharmacovigilance



Patient Involvement



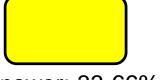
Decision Point



In what capacity are patient representatives involved in clinical trials?

Co-applicant	?
Trial Steering Committee	?
Trial Management Group	?
Data Monitoring Committee	?
Patient Advisory Group	?

Answer: 0-33%



Answer: 33-66%



Answer: above 66%



Co-applicant	26%
Trial Steering Committee	
Trial Management Group	
Data Monitoring Committee	
Patient Advisory Group	



Co-applicant	26%
Trial Steering Committee	83%
Trial Management Group	
Data Monitoring Committee	
Patient Advisory Group	



Co-applicant	26%
Trial Steering Committee	83%
Trial Management Group	30%
Data Monitoring Committee	
Patient Advisory Group	



Co-applicant	26%
Trial Steering Committee	83%
Trial Management Group	30%
Data Monitoring Committee	13%
Patient Advisory Group	



Co-applicant	26%
Trial Steering Committee	83%
Trial Management Group	30%
Data Monitoring Committee	13%
Patient Advisory Group	20%



Where did chief investigators feel the greatest level of impact of patient involvement?

Stage of involvement	
Trial set up	
Trial conduct	
Data analysis	
Dissemination	



Where did chief investigators feel the greatest level of impact of patient involvement?

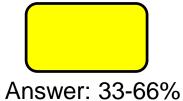
Stage of involvement	
Trial set up	2 nd (74%)
Trial conduct	1 st (82%)
Data analysis	4 th (7%)
Dissemination	3 rd (37%)



How did chief investigators involve patients in trial set up?

Designing/commenting on patient information sheet	?
Considering patient burden of participation	?
Determining outcomes to be measured	?
Considering visit schedules	?
Contributing to the recruitment process	?
Considering length and nature of follow-up	?
Helping to develop research question	?

Answer: 0-33%





6% Answer: above 66%



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	
Determining outcomes to be measured	
Considering visit schedules	
Contributing to the recruitment process	
Considering length and nature of follow-up	
Helping to develop research question	



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	
Considering visit schedules	
Contributing to the recruitment process	
Considering length and nature of follow-up	
Helping to develop research question	



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	46%
Considering visit schedules	
Contributing to the recruitment process	
Considering length and nature of follow-up	
Helping to develop research question	



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	46%
Considering visit schedules	43%
Contributing to the recruitment process	
Considering length and nature of follow-up	
Helping to develop research question	



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	46%
Considering visit schedules	43%
Contributing to the recruitment process	41%
Considering length and nature of follow-up	
Helping to develop research question	



Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	46%
Considering visit schedules	43%
Contributing to the recruitment process	41%
Considering length and nature of follow-up	36%
Helping to develop research question	



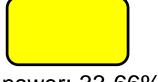
Designing/commenting on patient information sheet	84%
Considering patient burden of participation	80%
Determining outcomes to be measured	46%
Considering visit schedules	43%
Contributing to the recruitment process	41%
Considering length and nature of follow-up	36%
Helping to develop research question	27%



How did chief investigators involve patients in trial conduct?

Trouble shooting recruitment issues	?
Advertising to raise trial profile	?
Actively involved in recruitment/consent	?
Data collection	?
Participant identification	?

Answer: 0-33%



Answer: 33-66% Answer: above 66%



Trouble shooting recruitment issues	
Advertising to raise trial profile	
Actively involved in recruitment/consent	
Data collection	
Participant identification	5%



Trouble shooting recruitment issues	
Advertising to raise trial profile	
Actively involved in recruitment/consent	
Data collection	7%
Participant identification	5%



Trouble shooting recruitment issues	
Advertising to raise trial profile	
Actively involved in recruitment/consent	7%
Data collection	7%
Participant identification	5%



Trouble shooting recruitment issues	
Advertising to raise trial profile	27%
Actively involved in recruitment/consent	7%
Data collection	7%
Participant identification	5%



Trouble shooting recruitment issues	57%
Advertising to raise trial profile	27%
Actively involved in recruitment/consent	7%
Data collection	7%
Participant identification	5%





Clinical Trials Methodology Small Group Session

30/03/15





