

Today's challenges and opportunities in access to treatment

Case study: European Atlas of Access to Myeloma Treatment

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DECLARATION OF INTEREST



- Myeloma Patients Europe receives funding from Amgen, Binding Site, BMS, Celgene, Janssen, Medtronic, Novartis
- No personal conflicts of interest to declare

OVERVIEW

- MPE overview
- Setting the scene
- European Atlas of Access to Myeloma Treatment
- Why collaboration of clinicians and patients is important
- Conclusions

MYELOMA PATIENTS EUROPE



- Launched October 2011
- Registered as a non-profit patient association in Belgium
- 34 members, 24 countries
- Elected Board of Directors, mostly patients or relatives
- Project Manager & Operations Manager
- Funded largely by pharma, but other support too

OUR STRATEGIC OBJECTIVES

- Information, education, best practice exchange, outreach
- **Strategic capability & capacity building**
Sustainability of existing groups
- Evidence on needs of patients and their role in research
- Patient-centred research & clinical trials
Help to set up clinical trials where they do not currently exist
- **Minimum standards of care & timely access to new treatments**
- Shape health policy and initiatives at EU and national levels

SETTING THE SCENE IN ADVOCACY FOR ACCESS



EUROPEAN ATLAS OF ACCESS TO MYELOMA TREATMENT: A NEW ADVOCACY APPROACH

METHODOLOGY



OUTCOMES



Desk Research



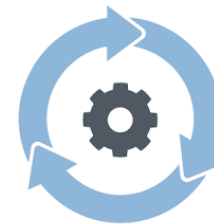
Survey



Report



**Interactive
map**



Implementation

CLINICIANS AND PATIENTS SHARE COMMON GOALS AND FACE COMMON BARRIERS

Perceived barriers to treatment

		Advanced disease stage due to late diagnosis	Lack of standard treatments	Cost/reimbursement of standard treatments	Lack of new treatments	Cost/reimbursement of new treatments	Lack of clinical trials	Slow drug approval process	Inadequate referral systems	Lack of collaboration across medical disciplines	Poor organisation of health care delivery systems	Bureaucracy	Treatment side-effects	Lack of supportive treatments	Time constraints of the doctor	Lack of professional training	Social stigma of cancer	Ethnicity of the patients	Lack of knowledge on the part of the patients	Unrealistic expectations from the patient	Patient non-compliance	Patient's difficulties in coping	Patient's families and friends difficulties in coping	Lack of patient support or self-help groups	Lack of training of caregivers	Lack of rehabilitation programmes	Cost/reimbursement of rehabilitation programmes
Very much	POs	19,2	11,5	7,4	26,9	29,6	29,6	30,8	11,5	11,1	12,0	22,2	15,4	11,5	19,2	7,7	7,7	3,8	22,2	3,8	7,7	3,8	7,7	7,7	11,5	26,9	30,8
	Exp	,0	3,6	3,6	3,6	10,7	17,9	25,0	,0	,0	7,1	3,6	,0	,0	3,6	,0	,0	,0	,0	,0	,0	,0	,0	7,4	3,6	7,4	3,8
Quite a bit	POs	26,9	7,7	22,2	3,8	18,5	11,1	26,9	19,2	22,2	4,0	18,5	23,1	15,4	7,7	11,5	,0	14,8	19,2	7,7	26,9	19,2	19,2	34,6	26,9	11,5	
	Exp	17,9	,0	7,1	25,0	32,1	17,9	25,0	7,1	10,7	,0	17,9	7,1	14,8	25,0	,0	10,7	10,7	10,7	10,7	7,1	3,6	,0	11,1	14,3	22,2	15,4
Moderate	POs	19,2	11,5	7,4	15,4	11,1	18,5	26,9	11,5	18,5	40,0	22,2	23,1	23,1	34,6	19,2	15,4	11,5	25,9	23,1	23,1	30,8	26,9	23,1	15,4	15,4	19,2
	Exp	35,7	17,9	10,7	35,7	17,9	17,9	35,7	25,0	21,4	10,7	25,0	21,4	14,8	14,3	21,4	14,3	10,7	35,7	39,3	17,9	14,3	11,1	25,9	28,6	22,2	19,2
Little bit	POs	30,8	23,1	14,8	38,5	22,2	29,6	15,4	19,2	37,0	28,0	18,5	23,1	19,2	34,6	26,9	50,0	11,5	33,3	42,3	46,2	30,8	34,6	34,6	15,4	26,9	23,1
	Exp	39,3	35,7	32,1	25,0	28,6	32,1	10,7	7,1	46,4	60,7	50,0	64,3	40,7	46,4	50,0	35,7	14,3	46,4	42,9	64,3	75,0	77,8	44,4	42,9	37,0	34,6
Not at all	POs	3,8	42,3	48,1	15,4	18,5	11,1	,0	11,5	11,1	16,0	18,5	15,4	30,8	3,8	30,8	26,9	65,4	3,7	11,5	11,5	3,8	3,8	11,5	15,4	,0	11,5
	Exp	7,1	42,9	46,4	10,7	10,7	14,3	3,6	,0	21,4	21,4	3,6	7,1	29,6	10,7	28,6	39,3	75,0	7,1	7,1	10,7	7,1	11,1	11,1	10,7	11,1	26,9
Do not know	POs		3,8						3,8									7,7			3,8	3,8	7,7	3,8	7,7	3,8	3,8
	Exp		,0						,0										,0		,0	,0	,0	,0	,0	,0	,0

IMPROVING ACCESS TO TREATMENT REQUIRES COLLABORATION, CONSENSUS AND TRUST

EVIDENCE

- Clinical evidence
- Identified barriers to access
- Data underpinning those access barriers

STRATEGY

- Clear and achievable goals
- Roadmap
- Learn from mistakes

SKILLS

- Training
- Capacity building
- Mentoring

CONCLUSIONS

- Access issues are complex and country-specific
- To date, advocacy on access to treatment of both patients and clinicians hasn't solved the issue
- Advocacy will only be effective if we...
 - join forces
 - have a thorough understanding of the underpinning issues and barriers
 - have empirical evidence, collected by patient organisations and clinicians
 - build a strategy, targeted solutions, skills
 - support implementation

→ THE EUROPEAN ATLAS OF ACCESS TO MYELOMA TREATMENT

THANKS!

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