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21TH INTERNATIONAL CONFERENCE FOR
ORGANISATIONS REPRESENTING PATIENTS
WITH CML



INVOLVING CMLADVOCACY IN SCIENTIFIC RESEARCH, HEMATON – THE NETHERLANDS

Jenny Borst, Hematon, The Netherlands

Advocacy Session #3
Best practice in patient advocacy
#CMLHZ23



Problem statement and background

- CML patients, haematologists, nurses and scientific staff should communicate at the same language level
- For all CML patients (including low literacy) it is important to be aware of the disease and treatment they are going to receive



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Implementation (I)

- The Radboud academy hospital started project CMyGuideline (2021)
- The goal: to gather patient wisdom for the optimizations of the guideline. Patient wisdom refers to side effects, medication and BCR-ABL values
- We made the guideline usable and applicable for healthcare providers, patients and their relatives in practice



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Implementation (II)

- Hematon became a partner in this project
- I got the chance to fully participate in the project.
- I was in contact with students covering a number of topics. They were asked by me: *'How are you going to do the research?'*

Implementation(III)

- Students from different study programs:
 - Literature
 - Communication
 - Medicine
 - Biomedical Science
- At their request, I gave them advice
- The dissertations clearly showed that the advice had been used



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Implementation(III)

- I missed by all the projects:

The importance of personal insight in to the symptom burden that chronic phase CML patients experience



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Result and Impact:

- The scientific article was published in Lancet Haematology
- A lot of attention for patients' views on their complaints



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Result and Impact:

- In the abstract: 'We kindly acknowledge the contribution of patient organisation Hematon - hematon.nl - and their patient representative Jenny Borst, in highlighting the importance of personal insight in to the symptom burden that chronic phase CML patients experience
- My goal has been achieved!
- I have been given the position of additional project group member scientific research cml



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Conclusion and recommendation:

- Contact the CML medical scientists and indicate what you are missing in their abstracts
- We learn from it and so do the CML medical scientists

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