

# USING A SOCIAL MEDIA PLATFORM FOR MPN PATIENTS

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Advocacy Session #  
Best practice in patient advocacy  
#MPNHZ22

## *Empowering patients requires patient interactions*

### *Why a social media platform?*

- 1. To learn from each other*
- 2. To share experiences*
- 3. To find relevant information*
- 4. To find other patients with similar medication, physician, hospital, MPN variant, nearby location, burden, age, gender, etc.*
- 5. In ones own pace and frequency*
- 6. To gather objective, usable data about MPN disease, medication and treatments*

## *Implementation (I)*

*Which social media platform to use?*

### *Facebook*

- *Interaction facilities (push messages, timeline, direct messages, etc.)*
- *Many users (600 at the time)*
- *Moderation capabilities*
- *Advertising and targeting*
- *Filtered time line by unknown algorithm*
- *Privacy concerns*
- *No advanced search function to find other patients*
- *No data collection*

## *Implementation (I)*

*Which social media platform to use?*

### *Forum*

- *search facilities for topics*
- *Many users (700 at the time)*
- *Relevant when having an urgent question*
- *Only question/answer. No real interaction*
- *No or too many push / e-mail messages*
- *No advanced search function to find other patients*
- *Limited analytics*

## *Implementation (II)*

### *Product selection: Hivebrite*

- *Well established product*
- *Excellent support*
- *Mature engineering team*
- *Scalable and robust*
- *Wealth of features*
- *Easy to maintain*
- *Extensive analytics*
- *Expensive*
- *App not adequate at the time*

## ***Implementation(III)***

- *Launched by E-mail invitation to all MPN patient members dec 2020*
- *Promoting platform via website, Facebook, magazine and annual meeting*
- *Keeping platform alive and relevant by adding content and*
- *Pushing vendor to invest in app*

## ***Result and Impact:***

- *Today we have more than 1000 participants*
- *The app has improved beyond “OK”*
- *Daily interactions*
- *Very high user rating*
- *Detailed data about medication, physician, hospital, MPN variant, nearby location, burden, age, gender, etc.*



## ***Conclusion and recommendation:***

*Interested? Visit us at our poster presentation.*

***Question: would you be interested to participate in a global, multi language, international expansion of the platform?***

*It would mean more patient interactions, more data, lower price.*

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