

# MPN GENIE QUALITY OF LIFE APP FOR PATIENTS, PHYSICIANS, RESEARCHERS

The Canadian MPN Research Foundation, Canada



**MPN**  
GENIE

**MPN** Canadian  
Research  
Foundation

Advocacy Session #  
Best practice in patient advocacy  
#MPNHZ21

### ***Problem statement and background***

***The MPN Community needs accessible Real-World Evidence and Patient Reported Outcomes, from sources that are not constricted by Medical Institutions and Academic Organizations. MPN Patients should have the ability to track their own symptom burden on their quality of life to stimulate a conversation with their Physician, in an area( psychosocial) that is often overlooked.***

### ***Why did you develop this project?***

Patient Empowerment – Documentation of the Burden of the disease on the Patient Quality of Life

Provide the Physician(s) the opportunity to see the whole view of the patient, not just a moment in time

Enable the Research Community the opportunity to see aggregated and anonymized data to help with new an ongoing research initiatives to investigate new therapies for MPN Blood Cancers.

## **Implementation (I)**

*How did you implement this project?*

*Outline key challenges and successes while implementing the project.*

- *Identified the key players Who is the APP for?*
  - *Patients, Physicians and Stakeholders(Research Community)*
- *Step One: Proposal made for grant funding*
- *Step Two: Identified the need From: Patient Perspective, Physician Perspective, Research Community Perspective*
- *Step Three: Sought input from MPN Community, Patients, Physicians and Researchers*
- *Step Four: Prepared the app based on input and then implemented the app for testing.*
- *Step Five: APP is now live and evolving in adding questions based on feedback from the MPN Community.*

## *Implementation (II)*

*key challenges and successes*

*Key Challenges:*

- *A key challenge, was just starting and knowing that the project will evolve.*
- *Ensuring that all stakeholders needs are taken into consideration.*

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

*How did you implement this project?*

*Outline key challenges and successes while implementing the project*

- *Once all stakeholder information was received, the Quality-of-life app was prepared, tested and implemented. Education of all stakeholders was and is important.*
- *Next steps of Globalization of the APP is very important.*

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

*What was the outcome, how did it make a difference for patients?*

*The impact on patients is just being measured, but the feedback received, has been phenomenal!*

*Giving patients the ability to have the knowledge and understanding of how their quality of life, impacts them and the burden of the disease may have on them, is very important.*

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

*What do you recommend to other MPN patient advocates if they want to do the same.*

- Work together in using the Quality-of-Life APP, for all MPN patients around the world.*
- MPN patients wherever they live, have the same burden on their quality of life and we need to have more accessible anonymized and aggregated data available to the research community have more impact on new treatment options.*

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