

What is Patient Advocacy ?

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Introduction

I am Jon Mathias, Co-Chair of MPN Voice, a patient support and advocacy group in the UK, and a founder and steering committee member of MPN Advocates Network.

Disclosures

Over the past five years, I have received honoraria from Novartis and GSK

MPN Voice and MPNAN receive grants from a wide range of industry sponsors to support our work

I also have a vested interest in MPN research and clinical practice, having been diagnosed with ET in 1998.



What is Patient Advocacy ?

I am going to talk about the work we do in MPN Voice and MPNAN to represent the MPN Community as a whole

This is different to a related role where an advocate speaks for an individual patient in very specific settings





Clinicians



Payers

*We exist in a
complicated healthcare
environment*



Industry



Researchers



Patient Advocacy



Clinicians



Patients



Payers



Industry



Researchers

Although patients are at the centre of this picture, often they have the weakest voice

Patient Advocacy



Clinicians



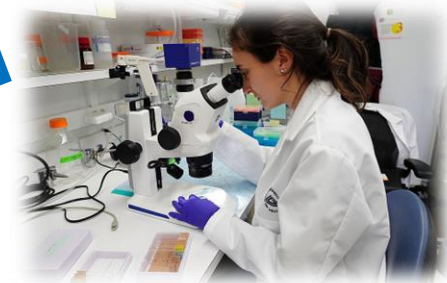
Payers



Industry



*Effective advocacy
creates a louder,
more consistent and
more focused voice*



Researchers

Patient Advocacy

As advocates for MPN patients, we need to create meaningful, honest and ongoing dialogue with

- **Payers** – “why do you not pay for this here?”
“do you really understand the burden of MPNs?”
- **Clinicians** – “why do you not use this drug here?”
“why can’t I be on this trial?”
- **Industry** – “why did you discontinue this research?”,
“does it really have to cost that much?”
- **Research** – “why does your trial not include quality of life endpoints?”

Patient Advocacy and HTAs

In terms of workload, my role as an advocate is mostly to engage with payers in the context of Health Technology Assessments

MPN Voice provides written submissions to NICE, SMC and NCPE, and we present direct testimony from patients to committee meetings

These decision-making bodies are increasingly interested in hearing the patient perspective and we position ourselves as the experts in the burden of the illnesses, alongside the clinicians and the economists



Challenges

The Advocacy function in MPN Voice and MPNAN is constrained by **capacity**.

We are almost entirely resourced by volunteers, most of whom have many other commitments - with more time, people and skills we would be able to engage more meaningfully with the stakeholders I identified earlier

We are beginning to see signs of an issue of **perception**

Because of our need to accept a proportion of industry funding, we are potentially open to questions of impartiality



Opportunities

One of the solutions to our capacity problem is **collaboration**.

MPNAN is part of a family of blood cancer advocacy networks, and MPN Voice works with other larger charities in the same field, sharing resources and best practice

Advocacy is on a path towards **professionalisation**

Advocacy education is growing in popularity, potentially leading to a world where advocates will practice alongside clinicians, researchers and other healthcare professionals

The question of how advocacy is funded needs to be addressed as the role evolves. It is essential that its independence is maintained



Thank you for listening

Questions ?

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