



# MPN GLOBAL PATIENT SURVEY

## INITIAL OBSERVATIONS

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# *Background and Context*

- The principal objective of the survey, which was launched in 2019, was to discover and document the differences between MPN Patients' experiences around the world.
- It is hoped that the data we gather will help advocates lobby for better access to therapies, expertise and information
- The initial observations we are presenting here are based on an informal view of the data we gathered in the first phase, and is limited to the responses we received then. It is not a detailed or peer-reviewed analysis.
- These responses were predominantly from the UK, the USA and the Netherlands.
- While we can already see some interesting differences, we do not yet have data from MPN communities in other countries and regions, where we might expect to see wider disparities.



# *Status of the Survey*

- The data on which these initial observations is based consists of 1734 responses received between December 2018 and November 2019.
  - 31% were from the USA
  - 23% were from the UK
  - 21% were from the Netherlands
  - The remaining 35% were from 49 other countries
- We are in the 2nd phase now, rolling out the survey to other countries, using medically reviewed translations of the same initial questions
- In parallel, we plan to conduct more formal analysis of the initial responses and to publish a paper about this analysis.
- We expect the survey to reveal the need to conduct deeper study into specific area and we plan to make the raw data available to advocates and researchers

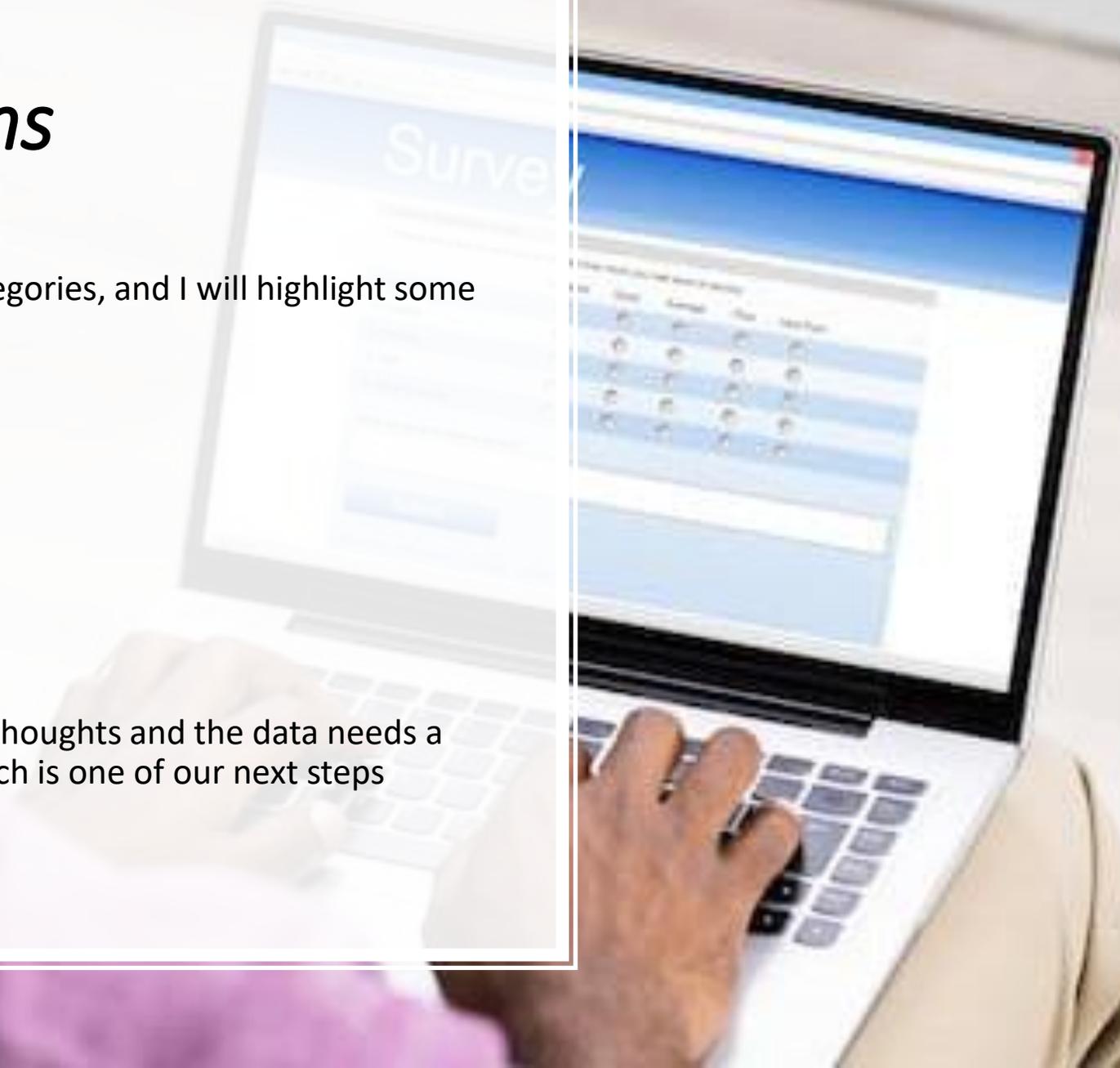


# *Initial Observations*

We asked questions in the following categories, and I will highlight some of the interesting points in each:

- Access to information
- Financial matters
- Support available
- Research and medical trials
- Treatment
- Information from physicians

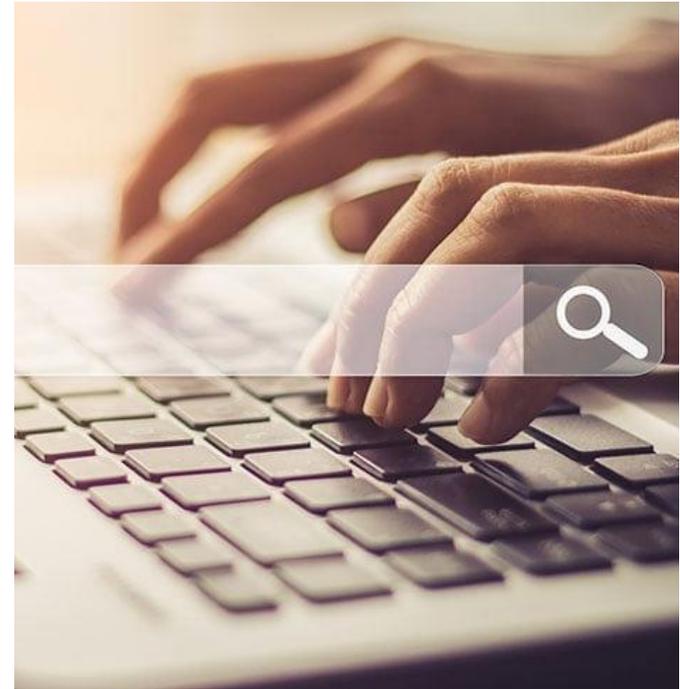
The following slides are simply my own thoughts and the data needs a more formal and complete analysis, which is one of our next steps



# Initial Observations – Access to Information

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- In the populations represented in Phase 1, Patients are generally happy with the information they have about the condition, slightly less about treatments available.
- Patients were much less satisfied with information available about alternative therapies
- Of the different ways of accessing information, Websites were most highly rated across all age groups
- Social Media was rated 2nd most highly in the youngest age group (<24 years), but 2nd least highly by the oldest (> 65 years)
- Printed material is the 2nd highest rated across all age groups



*The relative importance of social media to younger patients is probably expected, but the apparent continuing importance of printed material to all age groups is interesting for both clinicians and patient groups*

# Initial Observations – Finance

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- 41% of respondents pay for at least part of their MPN treatment (23% pay for all of it)
- 18% reported significant financial difficulties caused by their illness
- Respondents reported poor access to information about non-medical aspects of their condition
- Respondents were most concerned about the effect of their illness on employment. 17% were unable to work at all and 57% said that their illness affected their caregivers' ability to work



*As expected, there are significant differences between the financial issues faced by patients in different countries.*

*The economic impact of chronic illnesses is often overlooked but is an important factor in reimbursement policy.*

# Initial Observations - Support

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- Overall, 70% of respondents knew about a patient group in their country, but older patients were much more likely to be aware of one
- Awareness of support groups was lower in the USA (61%) and highest in the Netherlands (97%)
- 61% of respondents overall do not know other MPN patients. This is most clearly seen in Spain, but there seems to be more patient-patient contact in Japan. Respondents expressed a desire for more patient and support group contact
- There was overall dissatisfaction with the knowledge that General Practitioners had about MPNs. Women were less happy than men in this respect.
- Most respondents had access to an MPN specialist clinician, although 25% reported inadequate access to specialist expertise



*There may be some lessons to be learned by patient groups here in terms of awareness and publicity. In the UK, facilitating direct patient-to-patient contact is very popular and may be something other patient groups want to consider. GP knowledge is a common source of concern in the MPN community, and the data seems to support that concern. Given the relatively economically developed nature of the population in Phase 1, the fact that 25% have inadequate access to specialists is surprising*

# Initial Observations - Research

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- Generally, there is a low level of satisfaction with information about clinical trials. 27% said that they had no information at all.
- This dissatisfaction was most clear in younger age groups.
- Respondents from the Netherlands were most satisfied with information about trials.
- Overall, half the respondents said that they would be able to participate in a trial (assuming they were eligible)
- Interest in research general is very high. In terms of the preferred focus of research, 'treating symptoms' was rated almost as highly as 'finding a cure', with the causes of MPNs being slightly less important to respondents. In general, research is more important to younger patients.



*Any observations about awareness amongst age groups needs to account for the fact that older patients are generally more aware purely because of the longer period that they have been exposed to information.*

*But 27% saying they have no information at all about clinical trials is striking. The reasons for Dutch respondents knowing more in this respect would be interesting to explore.*

# Initial Observations - Treatment

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- In general, respondents seem to be happy that they are receiving the best available therapy for their specific disease, although 15% said that they were not. Over a third did not know.
- Data was gathered about the treatment prescribed at initial diagnosis.  
Aspirin, Hydroxyurea and Phlebotomy are the most common. Ruxolitinib (Jakavi) was prescribed for 7% of respondents and Interferon was prescribed for about 5% of respondents

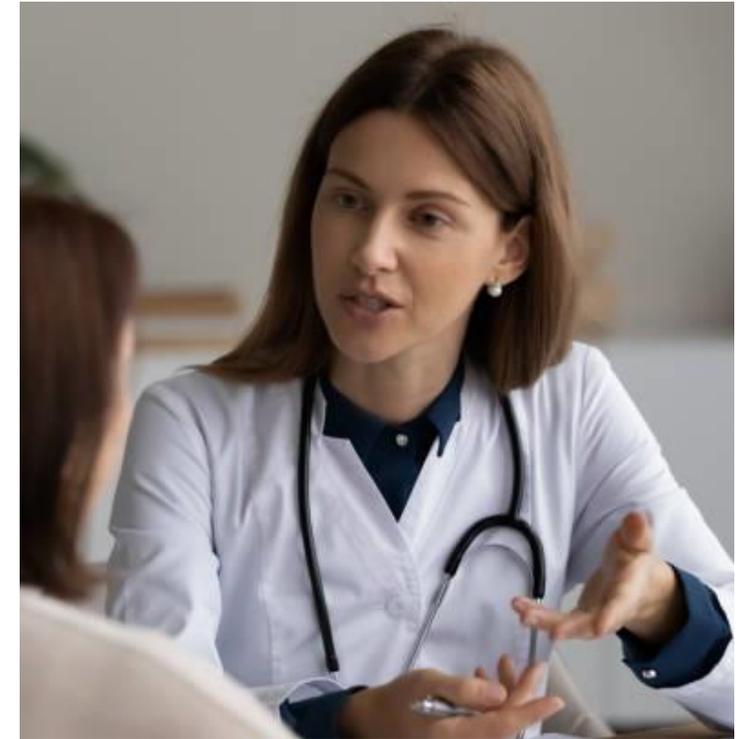


*The overall findings are not surprising, but this is a specific topic where further analysis of the Phase 1 data would be useful – e.g. to look at preferred treatment by disease type and country.*

# *Initial Observations – Information from Physicians*

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- 68% of respondents' doctors had provided information about treatment options, but nearly a third had not received such information.
- 59% of respondents said that they had not received information from their doctors about disease progression
- 39% of respondents overall had no access at all to psychological support, while 44% thought that this type of support would be beneficial



*Again, this data needs further analysis, but it is striking that a third of patients had not discussed treatment options. Availability of psychological support seems to be wanted, but often not available.*

