



# MDS National Survey

Assessing the needs for support

**Monika Janosik**  
**MDS UK Project Worker**

**The Lancaster Hotel London**

**3<sup>rd</sup> October 2014**

# Patient Surveys

## Cancer Surveys

- Cancer Patient Experience Survey, NHS England
- Prioritising Patient Need, Leukaemia & Lymphoma Research

MDS patients are underrepresented

## MDS specific surveys

- *Common troublesome symptoms and their impact on quality of life in patients with Myelodysplastic syndromes (MDS): Results of a large internet-based survey, 2007, US*
- *Quality of Life in Myelodysplastic Syndromes, Oncology Nurse Edition, 2008, US*
- *Valuation of transfusion-free living in MDS: results of health utility interviews with patients, Health and Quality of Life Outcomes, 2009, UK, France & Germany*

No UK specific study looking at MDS patient experience

# UK MDS Patients – Assessing the needs for support

- For individuals diagnosed with any form of MDS
- UK specific
- Anonymous
- Paper survey
- 30 – 40 min to complete
- Target 450 completed questionnaires

## Survey Contents

- Demographic questions
- MDS diagnosis process and information
- Your MDS subtype and MDS treatment
- Travel to hospital
- General support for MDS patients and carers

# UK MDS Patients – Assessing the needs for support

## Aims

- Learn about your patient experience
- Learn about the impact of MDS on your life
- Evaluate the services offered to you
- Identify health inequalities
- Identify changes over time

## Objectives

- Develop programmes to assist patients and families
- Educate physicians, nurses and allied healthcare professionals
- Work with governmental and private agencies/companies
- Collaborate with other charities (LLR)

Provide better care and services to you, the MDS patient

# Survey progress

- Phase 1 of data collection concluded – with 66 completed questionnaires
- Phase one data is currently being analysed – selected findings to follow
  
- Questionnaire is being revised and updated
- Survey distribution strategy is being revised to maximise recruitment and represent the MDS population at large
  - MDS UK members and non-members
  - In line with the distribution of 65+ population
  - Patients treated across different types of treatment centres
  - With/without access to Haematology Clinical Nurse Specialist (CNS)

# Who can participate

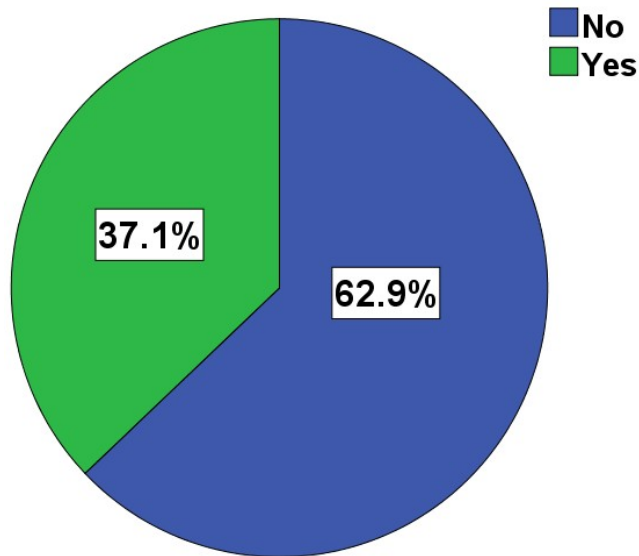
- Randomly selected sample from MDS UK members list
- Surveys attached with newsletters sent out to pre-selected hospitals in each UK region
- Surveys to be available to download from the website/order from our main office
- Support from our Members in survey distribution – please share with fellow MDS patients at your hospital!



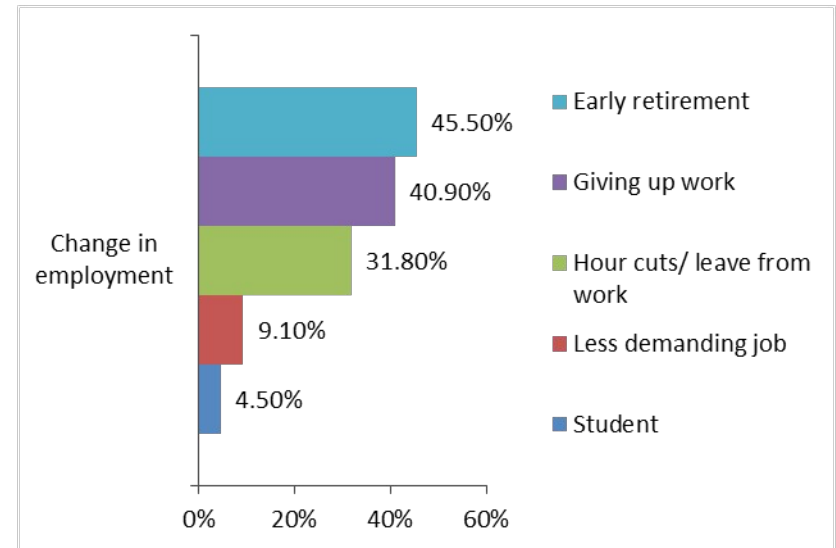
# Preliminary results\*

## Demographic questions

**CHANGE IN EMPLOYMENT STATUS AS A CONSEQUENCE OF MDS (n=62)**



**TYPES OF EMPLOYMENT CHANGE (n=23)**

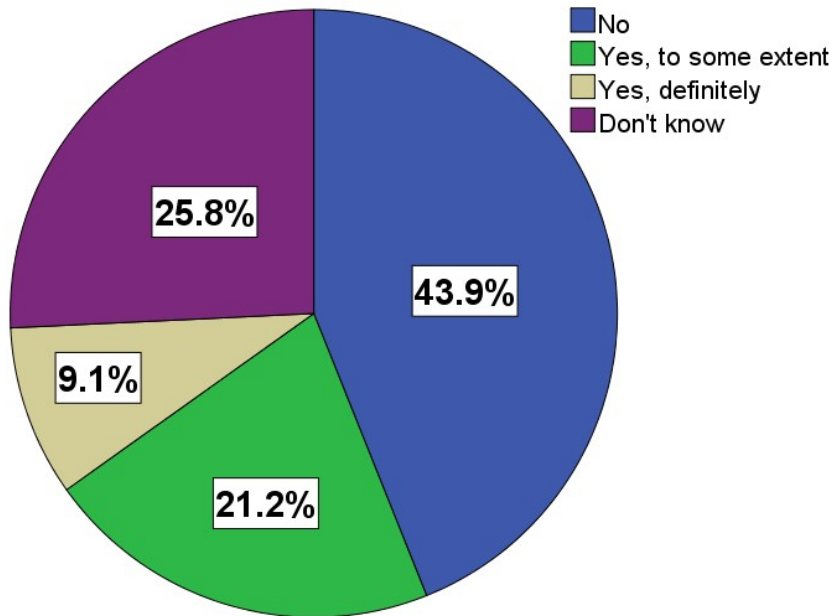


\* Please note that due to small respondent sample, the figures shown may not be representative of the wider MDS population

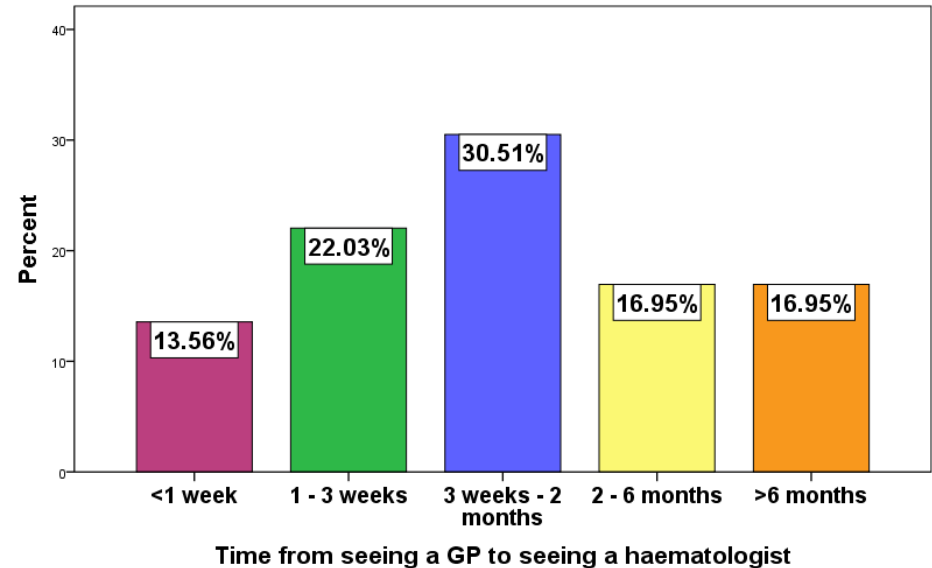
# Preliminary results\*

## MDS diagnosis process and information

GP'S AWARENESS OF MDS (n=66)



TIME FROM SEEING A GP TO SEEING A HAEMATOLOGIST (n=59)



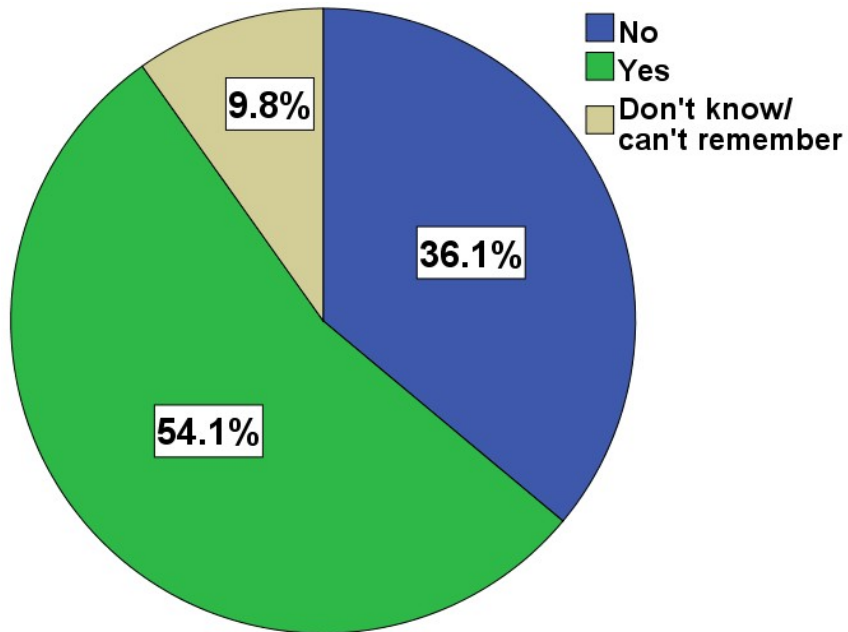
\* Please note that due to small respondent sample, the figures shown may not be representative of the wider MDS population



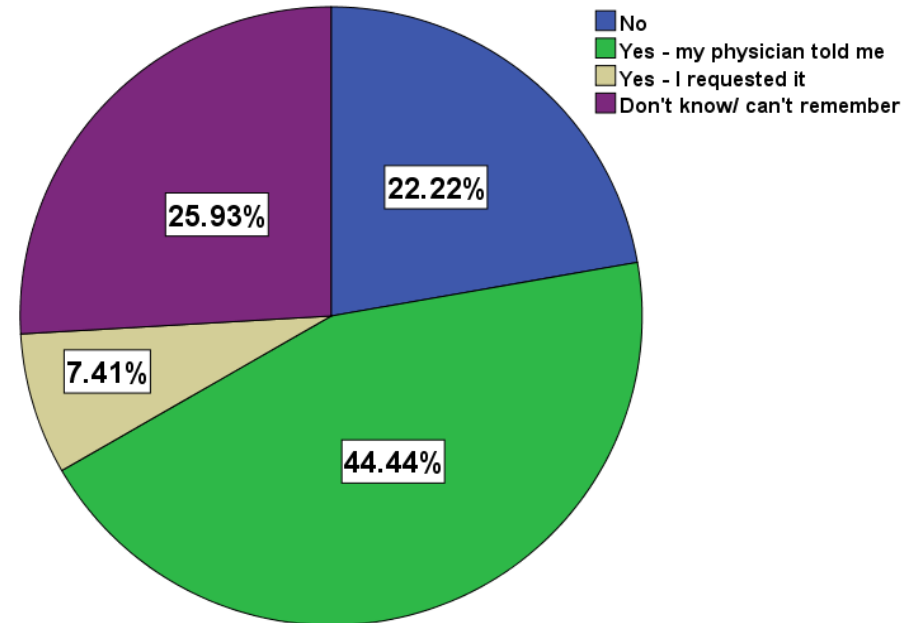
# Preliminary results\*

## Your MDS subtype and MDS treatment

KNOWLEDGE OF ONE'S MDS SUBTYPE AT DIAGNOSIS  
(n=61)



MDS SUBTYPE PROVIDED LATER (n=27)

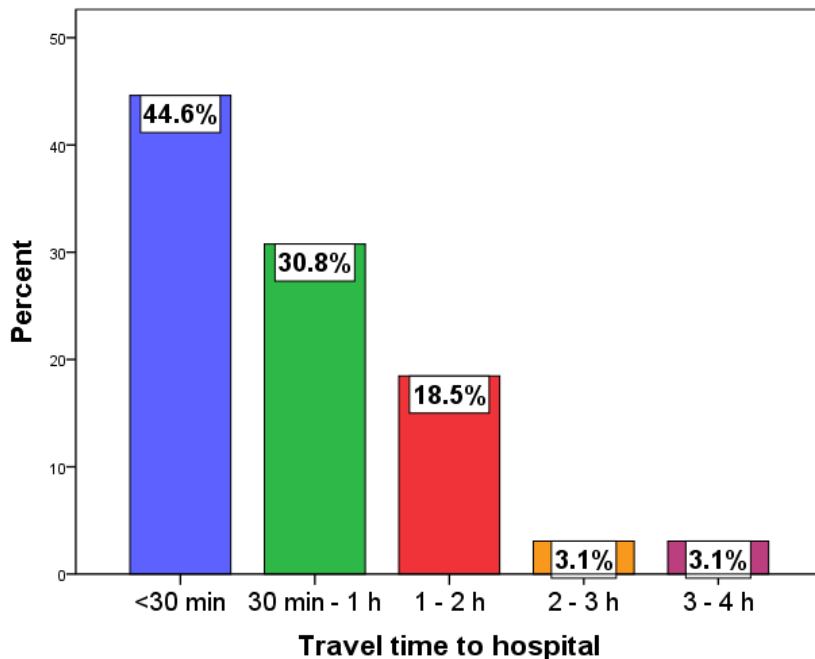


\* Please note that due to small respondent sample, the figures shown may not be representative of the wider MDS population

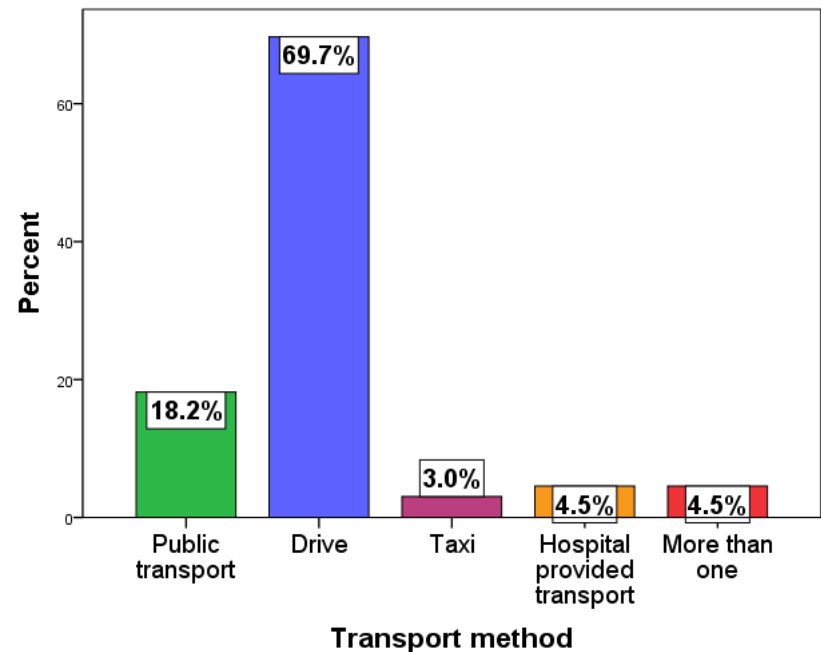
# Preliminary results\*

## Travel to hospital

Travel taken to hospital (n=65)



Method of transport generally used on travel to the hospital (n=66)

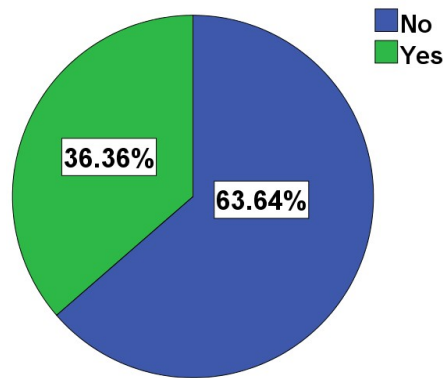


\* Please note that due to small respondent sample, the figures shown may not be representative of the wider MDS population

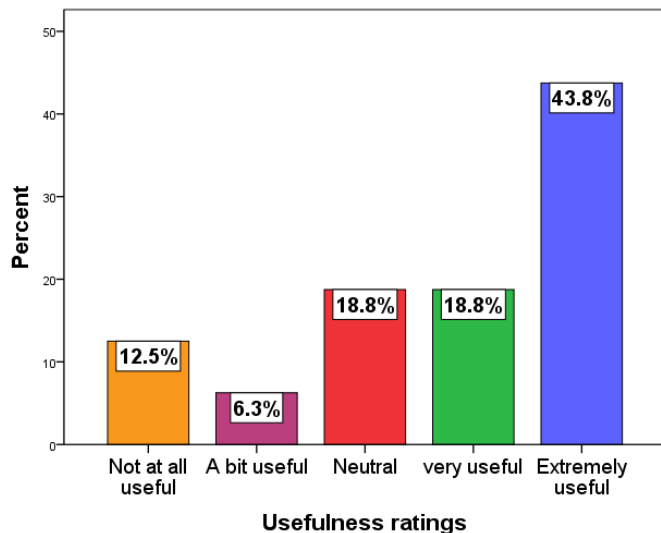
# Preliminary results\*

## General support for MDS patients and carers

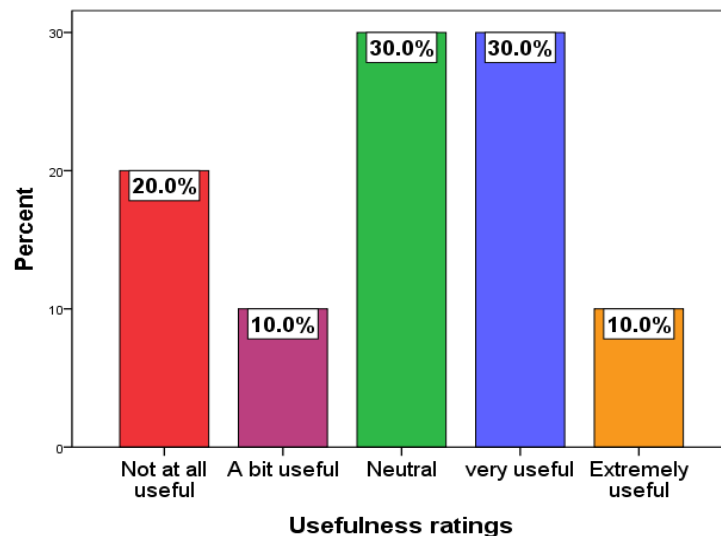
ATTENDANCE AT MDS UK MEETINGS (n=66)



MDS UK ANNUAL FORUM USEFULNESS RATINGS (n=16)



MDS UK LOCAL MEETINGS USEFULNESS RATINGS (n=10)



\* Please note that due to small respondent sample, the figures shown may not be representative of the wider MDS population

# Thank you!

Any questions, comments or suggestions?

Please come and talk to me, or alternatively...

Monika Janosik

Tel: 020 7733 7558

Email: [projectworker@mdspatientsupport.org.uk](mailto:projectworker@mdspatientsupport.org.uk)