



The European MDS Registry

EUMDS

<https://mds-europe.eu>

Twitter: @MDS_EUROPE

What is a clinical trial

- **WHO definition** – “any research study that prospectively assigns human participants or groups of humans to one of more health related interventions to evaluate the effects on health”
- **Interventional** –e.g. drugs used in new way, or novel agents tested to see how well they work and what side effects it may cause
- **Non- interventional or observational** e.g. EUMDS Registry

EUMDS Registry

- Aim to recruit at least:
 - 3000 patients with ‘low-risk’ MDS
 - 1000 patients with ‘high-risk’ MDS
- Collect information about newly diagnosed patient with MDS
- Present data using this information to further understand characteristics, outcomes and treatment of this disease.

EUMDS Registry

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- Recruiting since 2008
- 17 countries
- 2556 patients

- UK Recruitment (March 2019)
- 426 patients recruited across the UK
- 23 UK sites participating

EUMDS Recruitment



Austria	172
Croatia	22
Czech Republic	139
Denmark	60
France	514
Germany	64
Greece	326
Israel	224
Italy	90
Netherlands	103
Poland	57
Portugal	38
Republic of Serbia	34
Romania	45
Spain	135
Sweden	107
United Kingdom	426

UK Recruitment

Centre	Eligible	Eligible (New)*	Warnings	Warnings (New)*	AML	Lost to followup	Died	Followup Visit Count
Aberdeen Royal Infirmary (ABERD)	47	0	0	0	3	7	25	329
Airedale NHS Trust (AIRED)	28	0	0	0	1	2	19	133
Birmingham Queen Elizabeth Hospital (BIRMI)	1	0	0	0	0	0	1	1
Blackpool Victoria Hospital (BLKPLVC)	36	0	11	0	8	3	21	165
Bradford Royal Infirmary (BRADF)	16	0	0	0	3	0	3	63
Brighton (BRIGH)	0	0	0	0	0	0	0	0
Cambridge Addenbrookes (CAMBR)	11	0	0	0	0	1	5	29
Harrogate District Hospital (HARRO)	16	0	0	0	3	0	10	44
Huddersfield Royal Infirmary (HUDRI)	8	1	0	0	0	0	3	24
Hull and East Yorkshire Hospitals NHS Trust (HUEYO)	8	0	1	0	2	1	6	27
Leeds Teaching Hospitals (LEEDS)	112	0	0	0	14	6	42	288
Manchester Christie (MANCH)	1	0	0	0	0	0	1	1
Mid Yorkshire Hospitals (MIDYT)	14	0	0	0	6	0	7	57
Northampton General Hospital (NORTH)	20	0	0	0	3	4	11	100
Nottingham City Hospital (NOTTI)	7	0	2	0	2	1	2	44
Oxford Radcliffe Hospitals NHS Trust (OXFOR)	8	0	0	0	0	0	5	16
Royal Bournemouth Hospital (BORNE)	12	0	4	0	0	1	4	81
Royal Cornwall Hospital (TRURO)	11	0	1	1	2	0	4	101
Royal Victoria Infirmary (NEWCA)	7	0	0	0	0	0	6	27
Swansea (SWAN)	0	0	1	0	0	0	0	0
Western Infirmary Glasgow (GLASG)	6	0	0	0	1	0	3	49
Worcestershire Acute Hospitals NHS Trust (WORCE)	48	0	0	0	6	4	18	162
York Hospital (YORKH)	9	0	7	0	0	0	5	46

Subject Participation

- Newly diagnosed patients identified from our MDT and approached during clinic appointment
- Written consent taken
- Quality of life questionnaire to complete
- Height, weight, blood samples and medical history obtained for baseline
- 6 monthly collection of blood samples, weight and quality of life questionnaires, along with treatments, response and disease status.
- Consent can be withdrawn at any time
- Genetic testing part of blood testing - can be a tricky subject
- Contributing to a very valuable project which has already produced some useful results/information

Study Management

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- Clinical trial data management team
- Research nurse
- Data collection and entry
- Collection, storage and shipping of study samples
- Co-ordination with Sponsor

The Future

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- Newsletters for patients and their carers providing information about what we have found out so far.
- Recruiting more patients