

SMART – MND

Scottish Motor neurone disease Audit, Research &
Trials Project

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SCOTTISH MND REGISTER

- Established in 1989
- First Population Based MND Register
- Collected data over a 10 year period 1989 - 1998
- Multiple sources:
 - Notifications by MND specialist nurses
 - Hospital discharge and mortality data
 - Review of records
- Provided useful epidemiological data; incidence, prevalence etc
- Went into abeyance



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2010

- Wish to re-establish MND Register
- HIS Neurological Service Standards Established
 - Includes standards for MND
- Need to independently monitor standards of care
- Desire to attract clinical trials
- Establish a focus for further MND Research



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Scottish Motor Neurone Disease Audit, Research & Trials (SMART) Project

- In 2010, SMART project was established
- Multi Centre approach using the four neurological centres in Scotland
 - Aberdeen
 - Dundee
 - Edinburgh
 - Glasgow
- Multidisciplinary collaboration
 - Neurologists
 - Neurophysiologists
 - GPs
 - MND Nurses

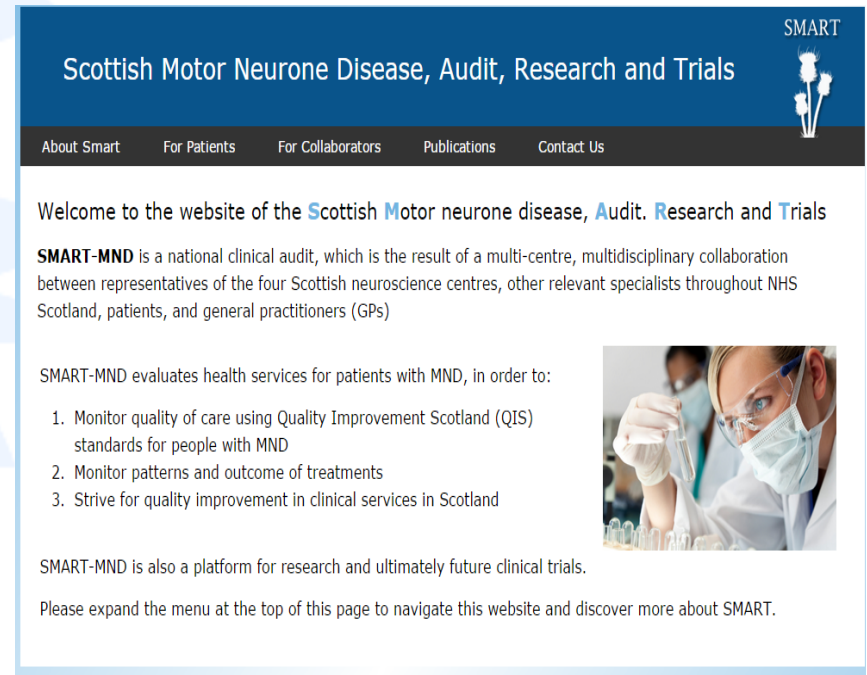


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GOALS

- **Incidence** to determine service needs
- **Prognosis** to assess outcomes and recruit to trials
- **Biobank** to provide resource for collaborators
- **Audit** to assess care



The screenshot shows the SMART website header with the title "Scottish Motor Neurone Disease, Audit, Research and Trials" and a navigation menu with links for "About Smart", "For Patients", "For Collaborators", "Publications", and "Contact Us". The main content area includes a welcome message, a description of SMART-MND as a national clinical audit, a list of three evaluation goals, and a photograph of a scientist in a lab coat and mask working with test tubes.

SMART

Scottish Motor Neurone Disease, Audit, Research and Trials

[About Smart](#) [For Patients](#) [For Collaborators](#) [Publications](#) [Contact Us](#)

Welcome to the website of the **S**cottish **M**otor neurone disease, **A**udit, **R**esearch and **T**rials

SMART-MND is a national clinical audit, which is the result of a multi-centre, multidisciplinary collaboration between representatives of the four Scottish neuroscience centres, other relevant specialists throughout NHS Scotland, patients, and general practitioners (GPs)

SMART-MND evaluates health services for patients with MND, in order to:

1. Monitor quality of care using Quality Improvement Scotland (QIS) standards for people with MND
2. Monitor patterns and outcome of treatments
3. Strive for quality improvement in clinical services in Scotland

SMART-MND is also a platform for research and ultimately future clinical trials.

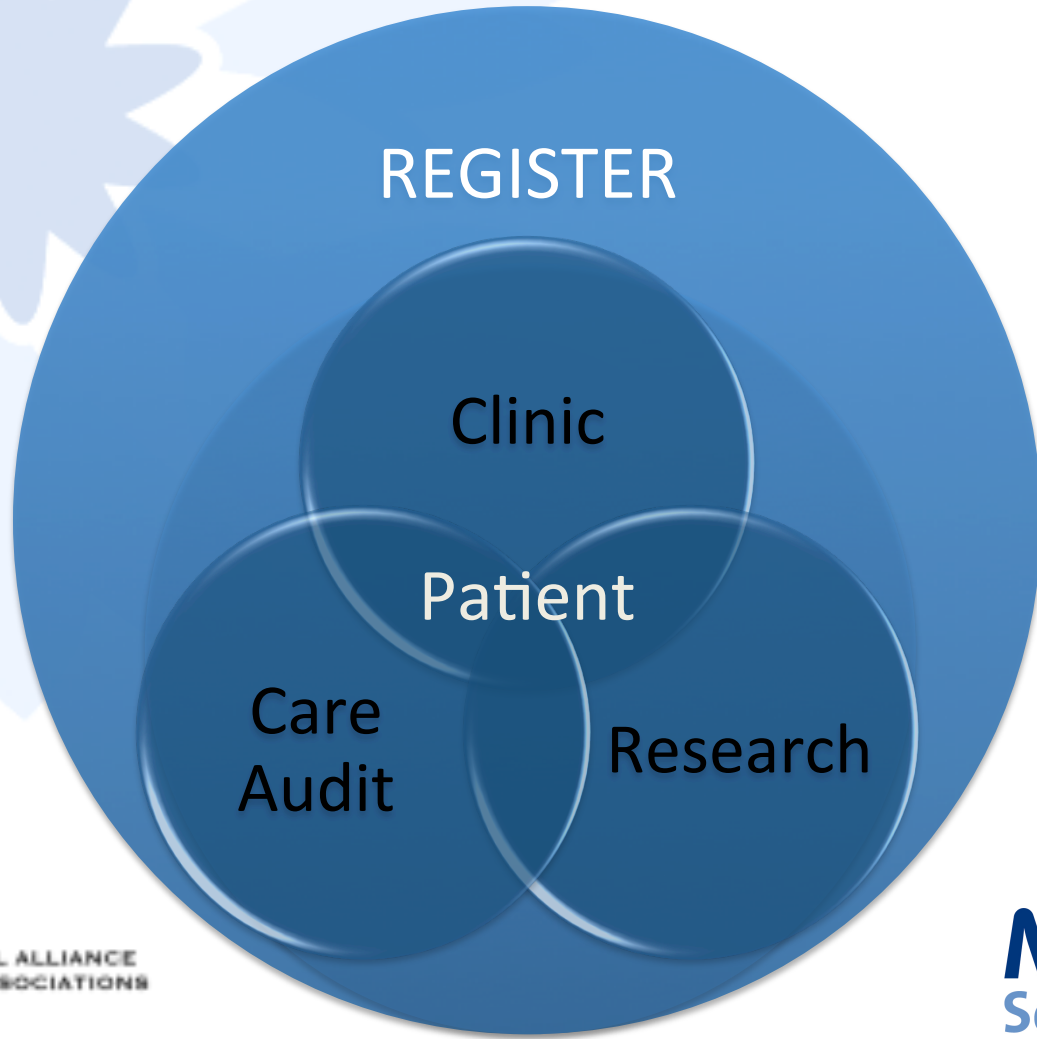
Please expand the menu at the top of this page to navigate this website and discover more about SMART.



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Process

- Initially relied on Neurologists
 - Didn't work
- Established MND Scotland Research Nurse who works in collaboration with the MND Clinical Nurse Specialists
 - Referral notifications
 - Add to audit database
 - Call patients & Invite for research
 - Add to register database
 - Review notes for audit/diagnosis
 - Scan records
 - Attend clinics
 - Visit some patients to collect info DNA
- Medical notes reviewed by neurologist and data inputted into register



Audit vs Register

Audit

- No permission from patients needed
- Data collected is non attributable

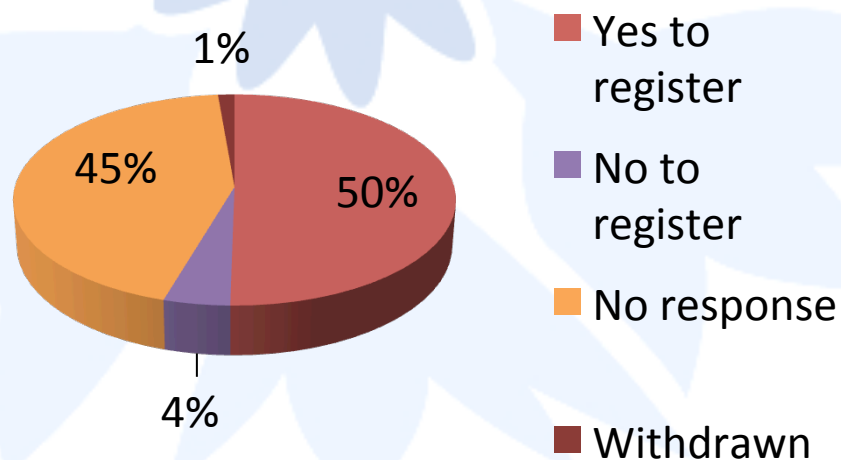
Register

- Patients need to opt in
- Documentation needs to be completed and signed
- Can opt to be involved in further research studies

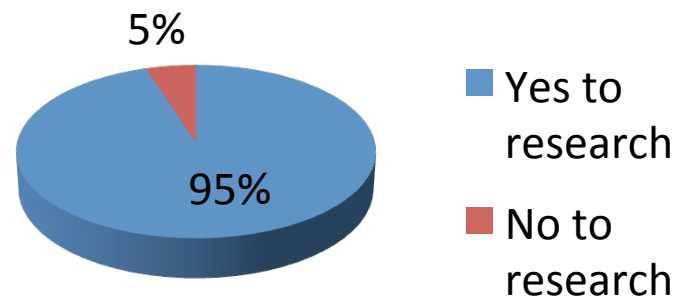


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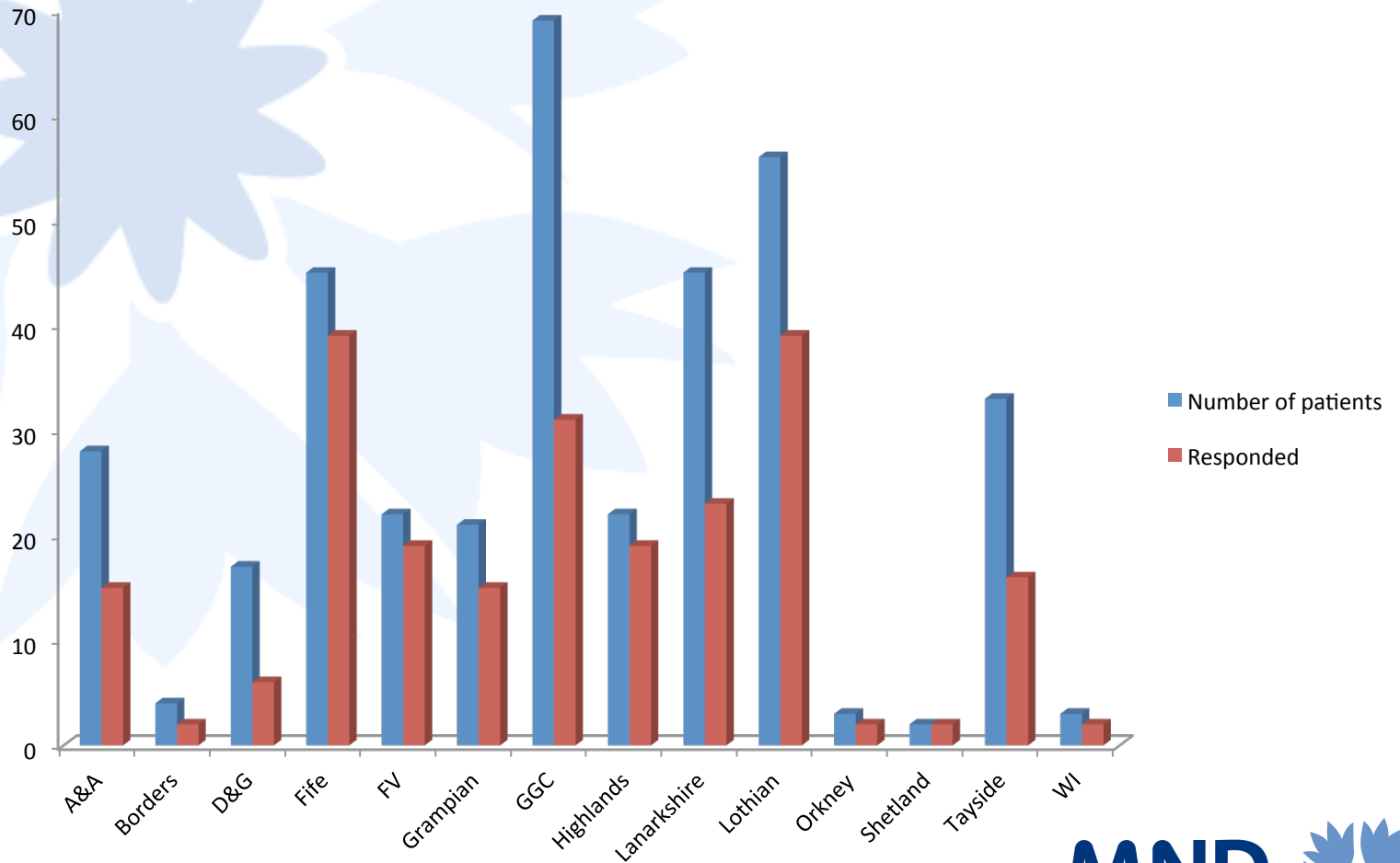
Responses to the Register



Of 'Yes to register'



Response Rate To Register



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Registrations To MND Register

1989-1998	SMNDR	1226
2011-2014*	Audit	1131
2011-2014*	Register	668 (59%)
1989-2014*	Total	2357

*06/10/2014



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Results - Sample



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Repeat the study of incidence in Scotland

...to find out if the condition is becoming more common, this will allow us to predict trends in prevalence, and model the demand for services

Year	1989-1998	2011
Population	5,125,000	5,295,000 (+3.3%)
N per year	123	160
Men	2.68 (2.48 to 2.89)	3.11 (2.47 to 3.87) (+16%)
Women	2.11 (1.94 to 2.29)	2.93 (2.33 to 3.61) (+38%)
Incidence	2.38 (2.25 to 2.52)	3.02 (2.57 to 3.53) (+27%)

(95% C.I.)



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Development of biological tissue resource and assessment of biomarkers.

3-1 DNA Bank

MND DNA Bank : 500 samples and controls

3-2 MRC Edinburgh Brain bank:

30 patients have donated brain and spinal cord tissue

3-3 MRC Regenerative Medicine centre:

Stem cell modelling -2 PNAS papers

3-4 Sharon Abraham Dept. Psychology

ECAS



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Audit Of Care Against HIS Standards

Standard 11 Access*	Yes (%)	No	NK
11.1b Seen by Neurologist	593 (97%)	20	192
11.1b MND service: neurologist & MND nurse	559 (91%)	52	194
11.2 MND service with full range of members	431 (75%)	147	227
11.3 MND care pathway available**	4 (21%)	14	0



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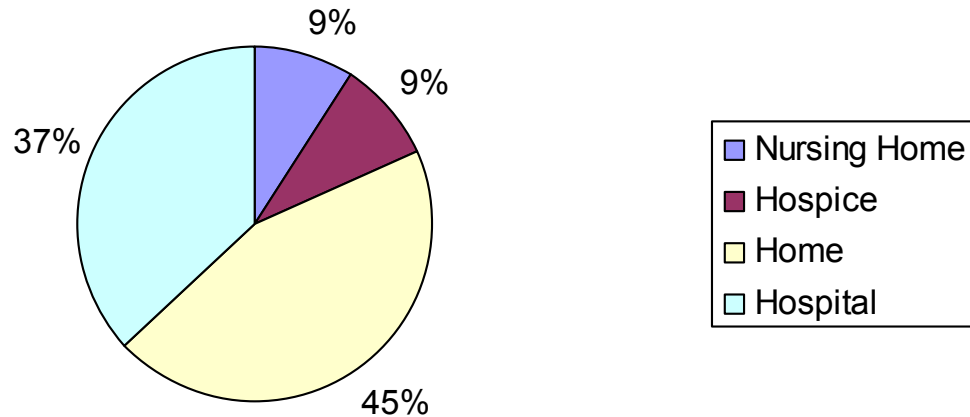
Audit Of Care Against HIS Standards

Standard 12 Diagnosis	Yes (%)	No	NK
12.1 MRI/EMG in 20 days	256 (51%)	245	304
12.2a Confirmed by a neurologist	555 (96%)	21	229
12.2b review within 15 days	287 (70%)	124	394
12.3a specialist nurse within two days	30 (4.9%)	581	194
12.3b info re voluntary services eg MND Scotland	217 (35%)	394	194



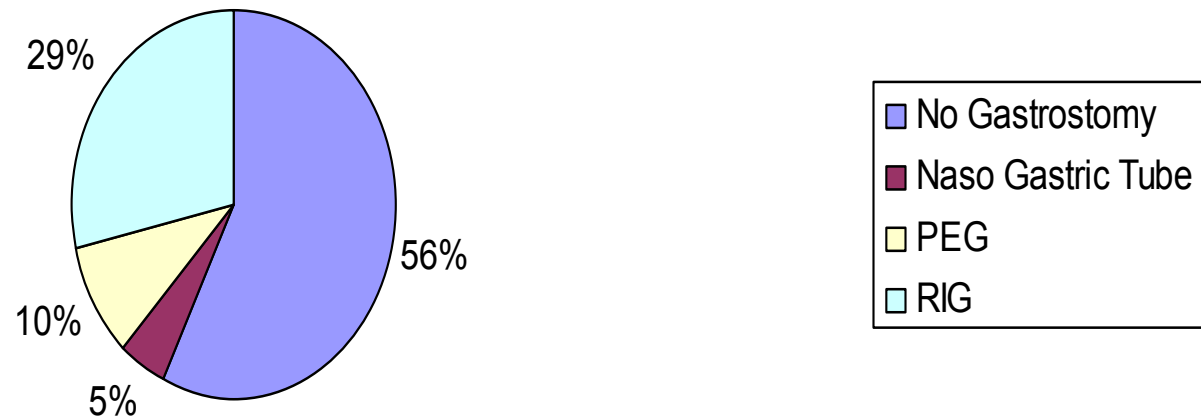
Glasgow Data 2012-2014

Place of Death of ALS/MND patients
2012-2014

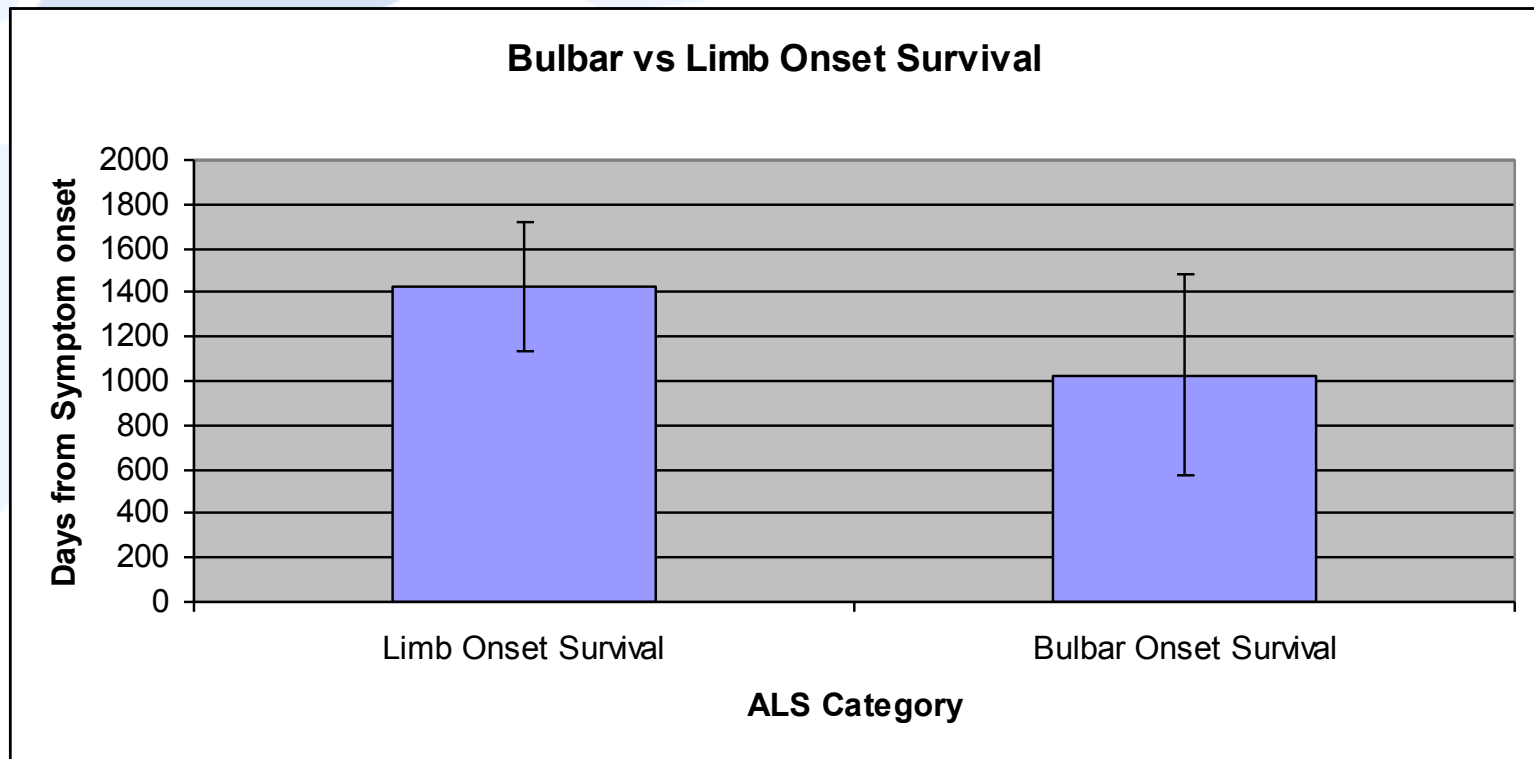


Glasgow Data 2012-2014

Artificial Nutrition in MND/ALS patients dying between 2012-14



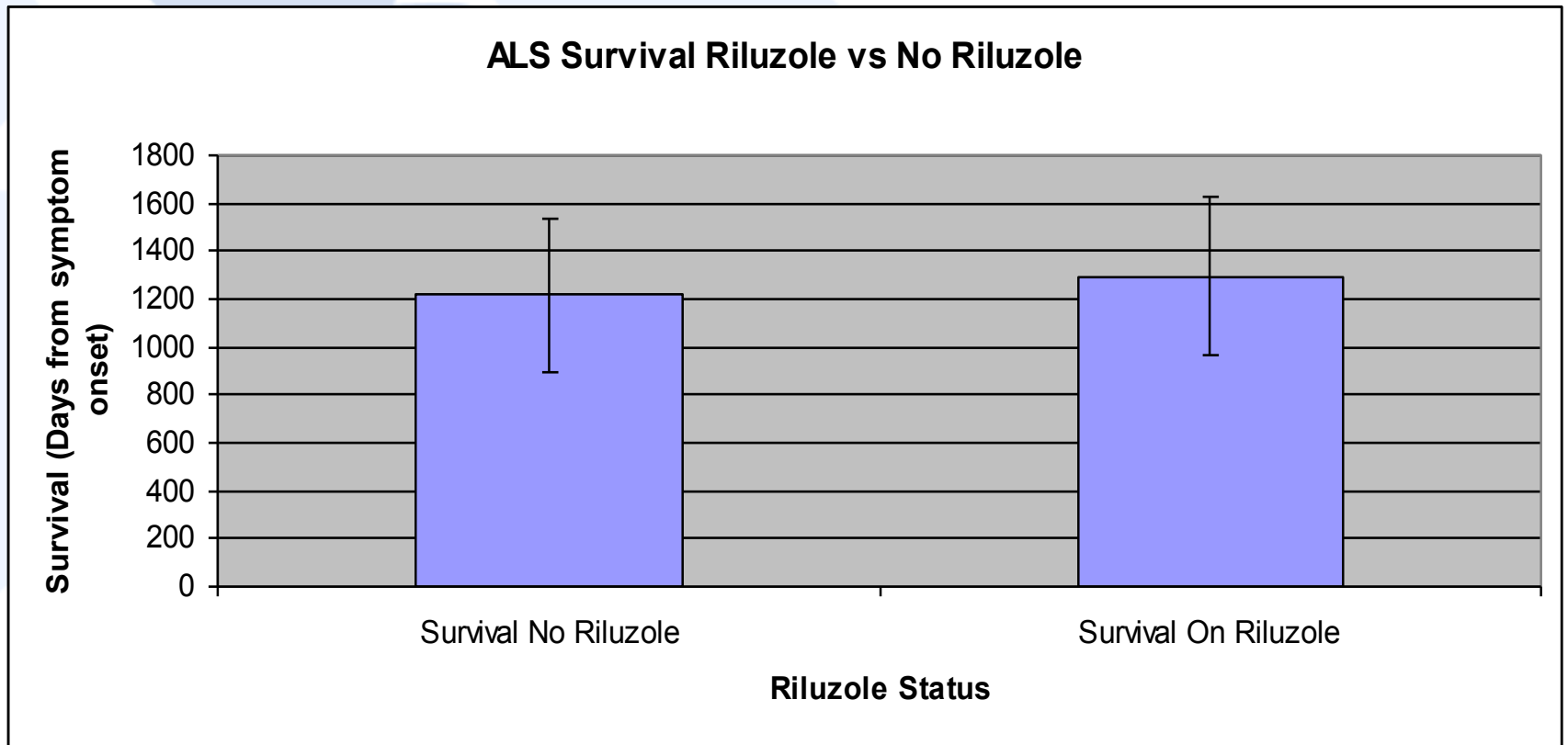
Glasgow Data 2012-2014



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Glasgow Data 2012-2014



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Going Forward

- Move from retrospective analysis to prospective
- Aim to increase recruitment rate to Register
- Standardise data collection from all sites
- Allow real time interrogation of data
- Three papers currently in production
- Use data to improve services



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