Brain and Spine 5 (2025) 105868

Contents lists available at ScienceDirect

Brain and Spine

journal homepage: www.journals.elsevier.com/brain-and-spine

# Early analysis of data from the British & Irish Brain Arteriovenous Malformations Registry (BIBAR)

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ARTICLE INFO

Handling Editor: Dr W Peul

*Keywords:*
Cerebral arteriovenous malformations
Registry
Radiosurgery
Surgery
Embolization

ABSTRACT

*Background and objectives:* It is important to establish a platform that allows methodical recording of treatments provided for brain arteriovenous malformations (bAVMs) which is a complex and heterogenous disease. In this preliminary report, the authors present the early analysis of the treatment of bAVMs from the British & Irish Brain AVM Registry (BIBAR).
*Research question:* Can a multicenter registry effectively capture bAVMs presentation and treatment data?
*Materials & methods:* The British Neurovascular Group (BNVG) set up a bAVMs registry working group in November 2018, with the primary aim of trying to ascertain the number and types of treatments provided for bAVMs across the United Kingdom.
*Results:* Between January 1, 2019 to December 31, 2023, treatment decisions were recorded for 1969 registered patients with bAVMs, of which 1713 patients received treatment at the time of the analysis. 56.28 % (964) patients had no evidence of rupture at the time of the initial treatment decision, whilst 43.72 % (749) presented with evidence of rupture at initial presentation. Of these, 83.31 % (624) were treated with radiosurgery, 13.62 % (102) with surgery and 0.93 % (7) underwent embolization. Age was negatively correlated with likelihood of surgical treatment. Patients who did not receive any treatment at the time of this analysis were not included.
*Discussion and conclusion:* We have shown that with a collective, collaborative effort, a national bAVM registry is feasible and as data capture becomes more complete, can provide valuable data on treatment types and volunes and provide an insight into the decision making underlying those treatments.

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https://doi.org/10.1016/j.bas.2025.105868
Received 9 September 2025; Received in revised form 28 October 2025; Accepted 9 November 2025
Available online 10 November 2025

**Abbreviations:**

bAVMs – Brain arteriovenous malformations
ARUBA - A Randomised trial of Unruptured Brain Arteriovenous malformations
SIVMS - Scottish Intracranial Vascular Malformation Study
NDR - national data registry
BNVG - British Neurovascular Group
UKNIG - United Kingdon Neurointervention Group
SRS – Stereotactic radiosurgery
SM – Spetzler – Martin
DSA – Digital Subtraction Angiography
NHS - National Health Service

## 1. Introduction

Brain Arteriovenous Malformations (bAVMs) (Lawton et al., 2015) are a complex and heterogenous disease associated with significant morbidity and mortality. 50 % of all intracerebral haemorrhages in patients younger than 40 years of age and 2 % of all haemorrhagic strokes are secondary to an underlying bAVM(Gross et al., 2019). The risk of haemorrhage from unruptured bAVMs under follow-up is 2–4 % per year, with an associated life-long risk of neurological impairment and complications and a risk of death of 10 % after an initial haemorrhage (Dicpinigaitis et al., 2023; Cognard, 2015; Link et al., 2018; Volovici et al., 2021). For ruptured lesions, the annual risk of haemorrhage increases to 4.5 % necessitating treatment to avoid future haemorrhages and neurological deficits (Yuan et al., 2024; Zhang et al., 2024). The New York Islands AVM study (Stapf et al., 2003) reported the incidence of first-ever haemorrhage to be 0.51 per 100,000 person-years and the prevalence to be 0.68 per 100,000.

There continues to be a spectrum of treatment modalities provided for both ruptured and unruptured AVMs. These include microsurgical resection, gamma knife radiosurgery (SRS), embolization or a combination of more than one of these modalities depending on the location and anatomical considerations of the bAVM. While there is a general consensus that on the rationale for treating ruptured bAVMs actively, the optimal management strategy for nruptured bAVMs remains debated across different neurosurgical centres, within United Kingdom and beyond. The ARUBA trial (Mohr et al., 2014) (A Randomised trial of Unruptured Brain Arteriovenous malformations), which was stopped early after an interim analysis that demonstrated the superiority of the medically managed arm added to the uncertainty to the management of unruptured bAVMs. Subsequent prospective and retrospective studies of ARUBA-eligible patients (Dicpinigaitis et al., 2023; Mohr et al., 2014; Link et al., 2018; Kim et al., 2025; Nadeem et al., 2023; Dodier et al., 2023) argued that it may not be necessarily representative of long-term outcome due to the short median follow-up of 33-months. The British Neurovascular Group, which is a representative body of neurovascular surgeons in the UK & Ireland, considered important to better understand the current volumes of treatment and treatment types for unruptured and ruptured bAVMs across the UK & Ireland.

Previous registries and cohort studies have explored more broadly, themanagement decisions/strategies for various bAVMs. For example the Scottish Intracranial Vascular Malformation Study (SIVMS) (Al- et al., 2003) and in the New York Islands AVM Study (Stapf et al., 2003) included “watch and wait” and the active monitoring for small and asymptomatic bAVMs or microsurgical resection for medium sized symptomatic or ruptured AVMs.

Endovascular embolization had been performed ed as an adjunct prior to microsurgical resection or SRS or as a standalone treatment, particularly for lesions that are considered too high risk for microsurgery or beyond the limits of technical feasibility for SRS. Stereotactic radiosurgery is a particularly useful treatment modality for deep-seated or surgically inaccessible bAVMs.

The rationale for the suitability of any given patient with a bAVM, for any of the treatment options, is often nuanced, but should in principle be centred around the goal of achieving complete obliteration of the bAVMs, and risk of further/future haemorrhage. The true frequency of the various treatment strategies for bAVMs in the UK & Ireland remains unknown due to different practices, between centres due to the availability of appropriate skill sets and access to the specialist tchnique. Currently, in England the NHS commissions stereotactic radiosurgery for bAVMs from two centres, and only recently extended to four centres in total.

With varying practices across countries and continents, it is important to establish a platform that allows methodical recording of the cases, decision-makling and outcomes. This platform should allow updates on patient’s progress, follow up imaging, and neurological outcomes. This creates a strong case for the formation of a national data registry (NDR) for AVMs. Development of a registry and evaluating outcomes of management of this low volume high complexity condition would allow streamlining of management protocols. This would assist in opening an avenue of a multicentric multidisciplinary discussion between neurosurgeons, and interventional neuroradiologists for best practice management of patients with ruptured and unruptured bAVMs.

The intention is for the registry to subsequently expand to provide data on a long term basis, for the natural history studies of both treated and untreated bAVMs. Recording of management decisions, treatments undertaken, obliteration rates and clinical outcomes long term would also provide data on treatment related morbidity for both unruptured and ruptured bAVMs.

In this preliminary analysis, the authors present an early analysis of treatment data for bAVMs from the first five years of the BIBAR across the 19 centres from the UK & Ireland.

## 2. Methods

The British Neurovascular Group (BNVG) set up a bAVMs registry working group in November 2018, with an aim to capture the management of bAVMs across the country. Invitations were extended to clinicians from the two NHS (National Health Service) commissioned SRS (stereotactic radiosurgery) centres, and the United Kingdon Neurointervention Group (UKNIG). The working group started with 14 clinicians from 10 neurosurgical units, including from the SRS centres.

This process was facilitated by the NIHR Brain Injury MedTech Cooperative by distribution of a questionnaire (Supplemental Digital Content 1) to the intended stakeholders in the working group. A working model using the secure online registry platform ORION (https://orion.net) provided by Orion MedTech Ltd. CIC, a not-for-profit social enterprise, was setup in 2019 and data has been collected from 19 out of 24 neuroscience units across the UK and Ireland since. A data sharing agreement outlining the data processing and sharing protocols between the participating institutions and the registry was completed. After institution specific (institutional review board approval for each site to allow anonymous patient data collection) approvals were obtained, patient data was extracted from hospital records and uploaded by dedicated clinicians from respective institutions.

All 19 centres are tertiary referral centres for management of bAVMs with atleast one sub-specialised neurovascular surgeons. The data dictionary was finalised to include detailed collection of demographics, presentation, imaging data, initial recommended treatment decision and actual treatment provided. This primary purpose of this initial phase of the registry, was to collect treatment-related data: that is, tretmeant type and related technical aspects for patients whose bAVMs were intended to be treated, following initial presentation or referral: data on conservatively managed bAVMs are not analysed in this report, as whilst a minority of centres chose to enter data on conservatively managed bAVM patients, others did not, as this was not the primary intention of

this registry.

Due to patients' being referred across the neurosurgical centres for different modalities of treatment, duplicate entries were avoided by use of a unique health ID tracker (in the UK, this was the patient's NHS number). For example, if a patient presented to Centre 1, and the treatment decision was for SRS, no treatment data would be submitted by Centre 1 (where there was no local SRS provision possible): instead when the patient presented for treatment at the SRS centre, the treatment data form would be completed using the same patient's tracked ID, which would be live on the ORION platform, and from which all of the pre-treatment data could be visualised. However, the patient would be attributed to Centre 1 as having been treated by SRS. However, if Centre 1 did not create a record for the patient when the patient was referred to the SRS centre, the SRS centre would then create a new record for the patient, and the patient would then be attributed to the SRS centre, as the centre of origin – this reflects practices in some centres where upon referral the neurosurgeon might expedite an immediate onward referral for SRS, rather than undertaking an initial local assessment first. This report outlines the data captured within the registry for the period January 1, 2019 to December 31, 2023, including from during the COVID-19 global pandemic period. The flowchart for registering of patients has been described in Fig. 1.

Statistical analyses were conducted using R and various associated packages (R Core Team, 2024). A standard student t-test was used for comparison between groups. A p-value $<0.05$ was considered significant.

## 3. Results

Between January 1, 2019 to December 31, 2023, 19 neuroscience units in the United Kingdom and Ireland registered 1969 patients with bAVMs. The aim of this analysis was to understand the volume and types of treatment strategies undertaken. Patients who did not receive any treatment at the time of this analysis were excluded, leaving data from 1713 patients whose treatment had been undertaken, to be analysed. The number of cases ranged from 3 per unit to 1025 cases per unit. Fig. 2 shows the distribution of the total number of AVM cases per unit. Duplicate entries were removed at the time of data analysis.

All data were anonymised, including the centre of treatment. High numbers of cases are seen in two centres (Centre 510 with 251 cases and centre 7 with 1025 cases) due to these centres being the two commissioned centres for all SRS treatment. Table 1 outlines the baseline demographics of all patients entered in the registry. Fig. 3 shows the overall trend in bAVMs being treated over the 5 year period, and by rupture status.

Fig. 4(A) shows the distribution of treatments across the 17 non-SRS centres. As large number of SRS treatment decisions would have been made in these centres, these treatments were attributed to the decision making centre, as the SRS centre would not, as a rule, decline SRS treatment. Fig. 4(B) shows the distribution of treatments across centres 7 and 510, which are the two commissioned SRS providers.

Fig. 5 shows the distribution of the actual treaments performed based on the presence of haemorrhage at the time of presentation. 56.28 % (964) patients had no evidence of rupture at the time of the initial treatment decision. 67.53 % (651) of these unruptured bAVMs were treated with radiosurgery, 24.27 % (234) underwent surgery, 3.53 % (34) underwent embolization and the remainder underwent multimodality treatment (combination of two or more modalities from surgery, SRS, and embolization). 43.72 % (749) presented with evidence of rupture at initial presentation. Of these, 83.31 % (624) were treated with radiosurgery, 13.62 % (102) with surgery and 0.93 % (7) underwent embolization.

In this registry, an initial intended treatment was recorded in addition to the final management strategy implemented. We evaluated those patients who were planned for treatment but did not receive any treatment at the time of analysis. 58 patients with ruptured bAVMs and 78 patients with unruptured bAVMs were planned for treatment but did not intentionally receive any treatment. Fig. 6(A) and (B) shows the changes from intended treatment to final treatment. 11.8 % overall had a change in the final treatment delivered compared to the intended treatment, 2/3 of these were unruptured bAVMS, and Table 4 shows the breakdown by SM grade for these groups, 93.90 % (1540) of patients had DSA as the definitive imaging investigation for diagnosis of the bAVM; the remainder were diagnosed by MRI. 16.46 % (270) of bAVMs were SM Grade 1, 42.50 % (697) were SM Grade 2, 31.22 % (512) were Grade 3. Grade 4 and Grade 5 formed a smaller proportion of the registry, similar to data from other international bAVMs registries. Table 2 shows the distribution of the SM grade distribution between unruptured and ruptured bAVMs. Table 3 shows the treatment modalities based on the SM Grades across ruptured and unruptured bAVMs. The results are also presented in the form of a bar chart in Fig. 5.

Table 5 shows the distribution of treatments, between older and younger patients, with division by age being those aged less than or equal to 70 years and those older than 70 years. A Chi-square test between these groups showed no significant difference in the choice of treatments undertaken (p-value = 0.74). To understand this further, a univariate logistic regression was performed for choice of treatment. Table 6 shows the intercepts and corresponding p-values for each treatment. Fig. 7 shows the probability distribution across the age groups for the 2 treatments of surgery and radiosurgery. Whilst the results do not show a significant change in choice with respect to age, older age appears to negatively influence the decision to offer surgery.

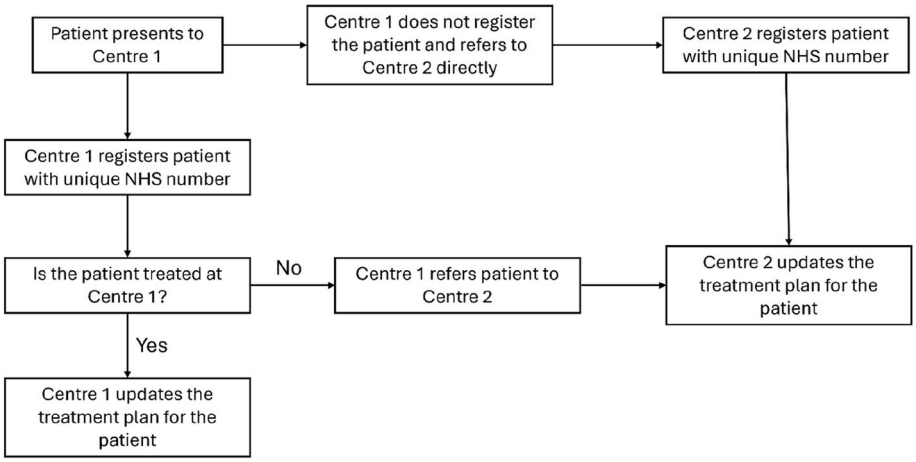


**Fig. 1.** Flow chart describing the registering of patients on the ORION platform.

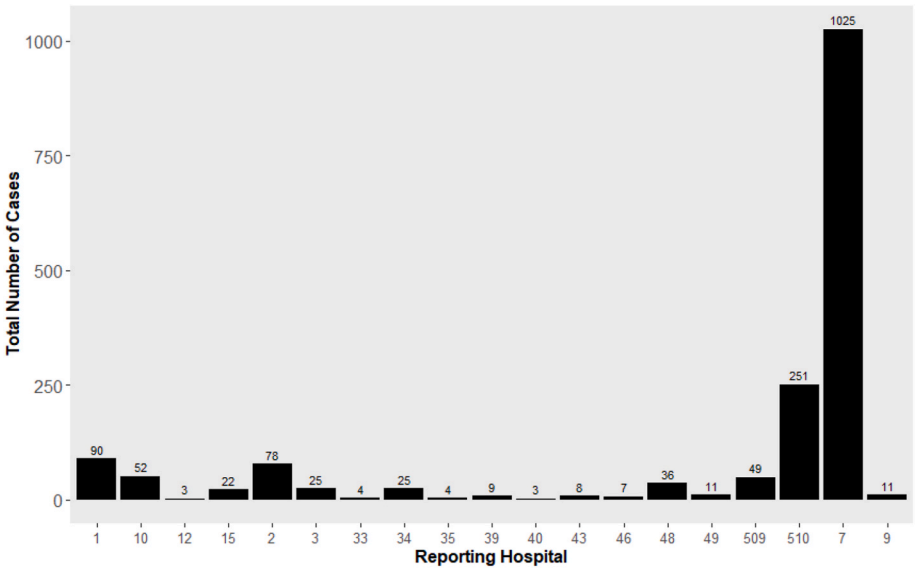


**Fig. 2.** Bar chart reflecting the cases treated by each reporting institution. Each reporting institution was given a reference number for anonymity.

**Table 1**
Baseline demographics.

| |
|---|
| Total number of patients 1713 |
| Age 44.50 (median 45) |
| Males 906 (52.89) |
| Females 807 (47.11) |

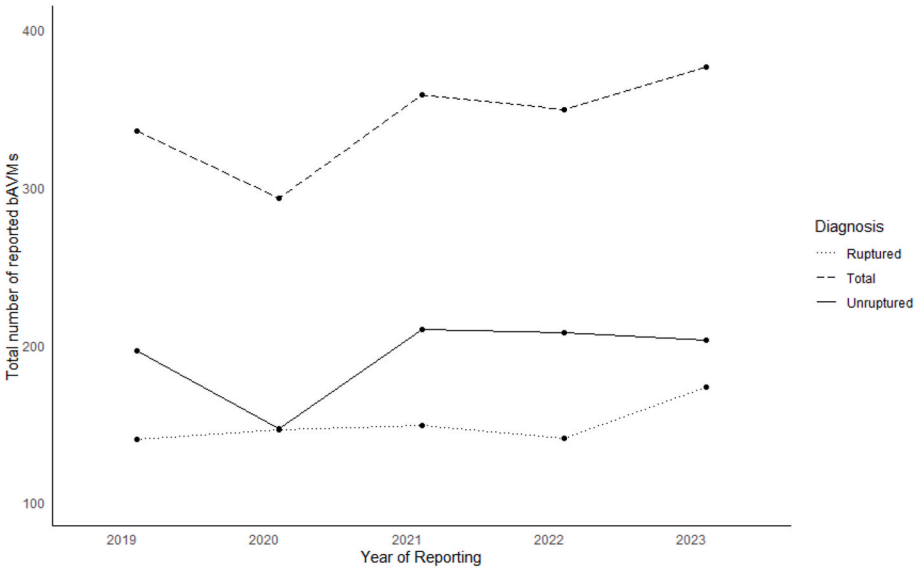


**Fig. 3.** Yearly trends representing ruptured, unruptured, and total bAVMs from 2019 to 2023.

Fig. 8 shows the violin plots for the 4 treatment modalities.

## 4. Discussion

bAVMs are a complex neurosurgical pathology with a myriad of management strategies. A dedicated registry with multicentric data collection was developed in an attempt to ascertain the types, volumes and distribution of bAVM treatments in the UK & Ireland: other studies have looked at wider management aspects such as the natural history of untreated and ruptured bAVMs. Of the 24 neuroscience centres in the UK & Ireland, 19 actively entered data into BIBAR over the 5 year period; the main impediment to the remaining 5 centres not providing data seemed to be related manpower and resource support, rather than any objection in principle, a situation that is anticipated to be resolved in time.

The initial stage of the registry development was focussed on an attempt to capture all treatments provided for bAVMs in the context of initial treatment intent decision, that is in patients for whom an active intervention was recommended, irrespective of whether they presented with a bAVM related haemorrhage or had an unruptured bAVM. Conservatively managed bAVM were not routinely collected in this registry, as the intention was to understand the spectrum of treatments

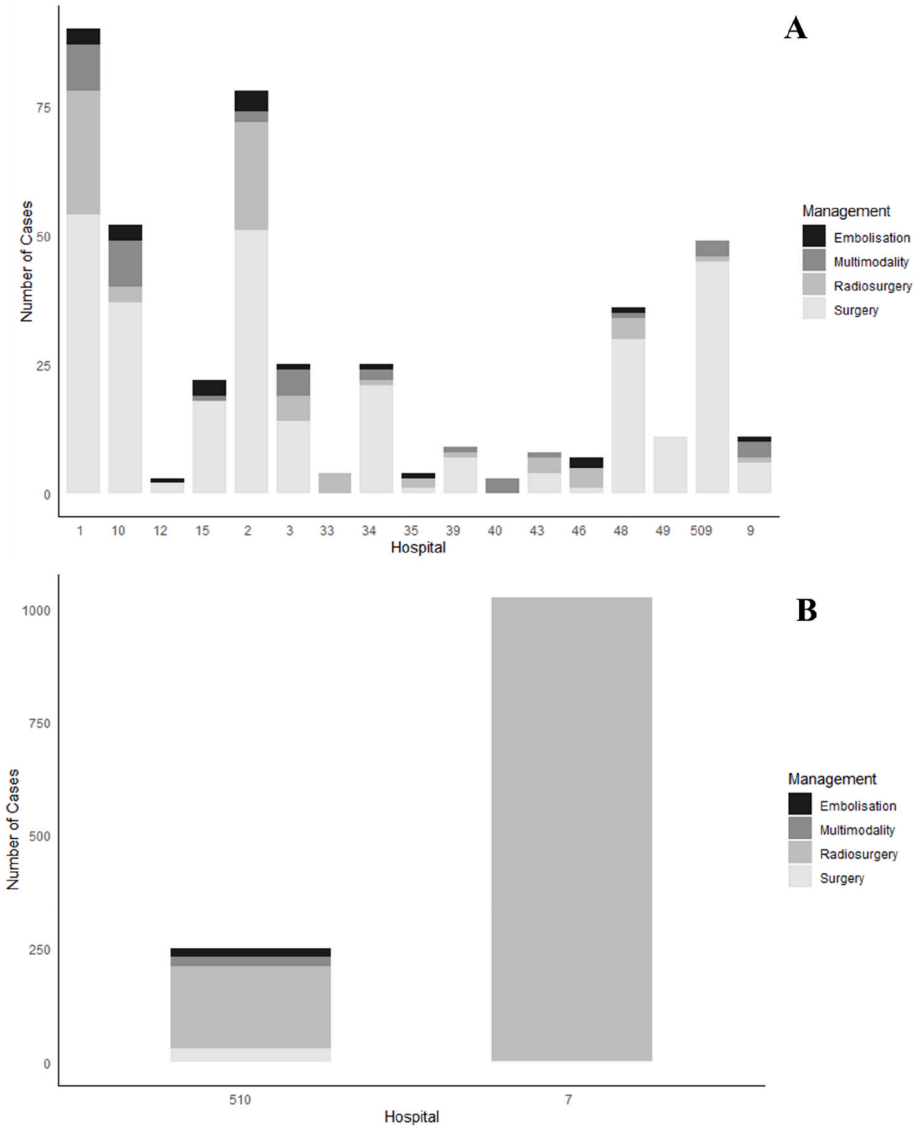


**Fig. 4.** (A) Treatment modalities instituted across each hospitals except for the 2 commissioned centres for SRS (B) Treatment modalities instituted across each hospitals except for the 2 commissioned centres for SRS.

offered rather than as an observational study for conservatively managed bAVMs. Data from the other 5 eligible bAVM treating centres was not available either because the centres had not fully enrolled into the Registry (data sharing agreements not finalised), or were awaiting administrative support for data entry; no eligible centres withheld consent for participation.

The total number of bAVMs patients being enrolled into BIBAR remained relatively consistent over the past 5 years, with the lowest numbers reported in 2020, at 293 cases. This could be attributed to a decreased number of cases being reviewed, due to the then, COVID-19 pandemic. There was a lower number of unruptured bAVMs cases in 2020, 147 compared to 196 in 2019. As the registry was only set up in 2019, initial uptake and data entry is expected to be slow. With further strain on manpower during COVID, this would be further affected. There was no reduction in the number of the ruptured bAVMs reviewed during this year (140 in 2019 as compared to 146 in 2020). There was a rebound increase in total cases reported in 2021, with the numbers returning to 359 and have remained stable since for both ruptured and unruptured bAVMs.

A recent study by Ramsay et al. (2024) showed that there was a significant reduction in the number of unruptured bAVMs in 2020, in the National Inpatient Sample database in United States. The analysis of the current registry data, mirrors this finding, largely reflecting the approach taken by global healthcase systems to non emergency conditions.

The two commissioned centres for SRS, centres 510 and 7, accounted for the majority of the attrition for SRS treatment. As seen in Fig. 2, the case load was variably distributed across the centres. Disproportionately higher number of cases are recorded in the two centres which are commissioned for SRS treatment in England. To avoid duplicates and data loss, a decision was made to 'lock' the centre of treatment (Fig. 1), at the time the patient record was created. The small number of patients attributed to non-SRS centres, is attributable to the patient record being created at a non-SRS centre, where the patient first presented, before being referred for SRS. Centres 510 and 7 created the patient records for the majority of the patients being treated, reflecting higher attributed numbers to those two centres. Fig. 4(A) gives further insights into understanding the management across the centres with varying resources (Refer to Supplemental Digital Content 2 for details on management by each centre).

A large number of patients in both ruptured (67.53 %) and unruptured (83.31 %) bAVMs underwent SRS. These numbers are higher as

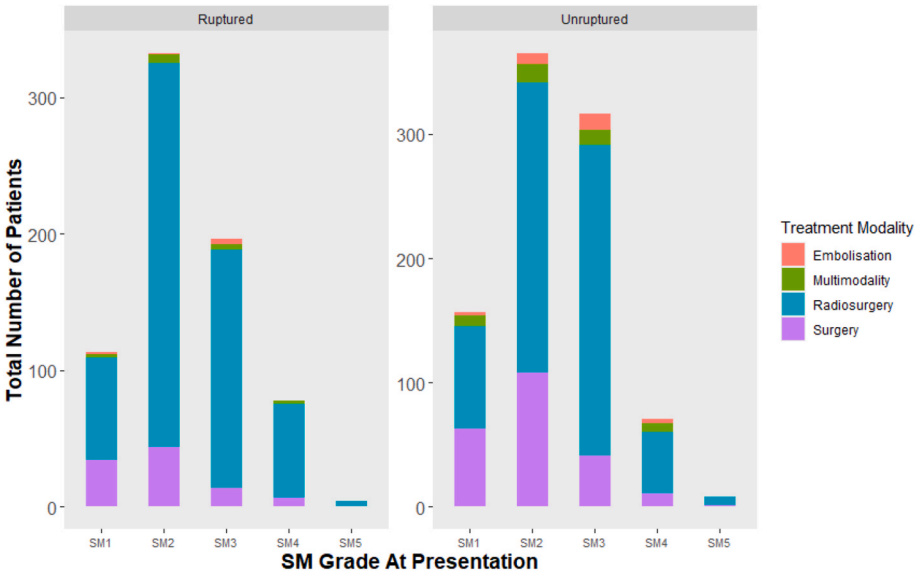


**Fig. 5.** Treatment modalities instituted across ruptured and unruptured bAVMs based on the SM grade at the time of presentation.

compared to the other reported cohorts analysing bAVMs (Al- et al., 2003; Link et al., 2018). At this juncture, it is difficult to ascertain the reasons for this disparity and we can only speculate, whether surgical expertise and/or low volumes in several units may have had an impact on the decision making; this requires subsequent analysis.

Centres 33, 39, 40, 43, 49 and 509 did not record any cases undergoing embolization. This may reflect the experience and expertise of interventional neuroradiologists in those centre in performing transarterial or transvenous embolization, or may reflect an active nuanced decision to not consider that treatment strategy for the particular bAVM.

As this registry was completed by the neurosurgical team, patients that may have been admitted under a neurologist for example, or primarily assessed by neurointerventional radiologists, might have been missed (both likely to be a small minority, as the practice within the UK & Ireland is such that patients would usually be admitted for bAVM embolization under the care of a neurosurgeon).

More detailed evaluation of the patients and bAVMs undergoing either adjuvant or curative embolization, might shed light on the decision making behind the treatment selection; something which is being developed for the next phases of data collections.

All centres except centre 33 and 40, performed surgical intervention of varying volumes. As all centres were represented by vascular neurosurgeons, this result is not surprising. All bAVM treating centres, including those not currently submitting data to the registry, would have capabilities of providing both microsurgical and embolization treatment options, if deemed appropriate; however, experience in performing both treatment paradigms is likely to vary from centre to centre, and this may affect some of the treatment intent decisions that were made.

However, the lack of SRS availability in every centre is unlikely to have the same impact on decision making, as an understanding of the indications, suitability, efficacy, and complications of SRS treatment for bAVM would fall within the competencies of all neurovascular neurosurgeons, and this information would be considered at the time treatment intent was discussed at the multi-disciplinary forum. This analysis therefore does not focus on the reasons underpinning the management decisions, and focusses on the types of treatments that were performed.

As seen in Fig. 6(A) and B, where intended treatment and final treatment was compared, there were several patients in whom the treatment performed was not that which was initially intended, or for whom no treatment was performed. 58 patients in the ruptured bAVMs and 78 patients in the unruptured bAVMs group were planned for treatment but did not receive any treatment at the time of analysis. In some cases, this will be because of the lag period to receiving treatment; for instance, if patients were registered towards the end of the data collection period, with an intention for treatment to be performed, they may still have been awaiting a date for that treatment. In other cases, this may simply reflect local practice for batch inputting of treatment data, in a delayed manner.

The number of patients who had a change from the intended treatment modality to an alternative treatment strategy/modality was 197 (10.89 %). The current registry does not capture the reasons that underpin the change in treatment intent or at what stage that had occurred, but based on the SM grade breakdown we can speculate that this may be related to eloquence as this ‘cross-over’ seems to have been more common in SM 2 & 3 patients, with the largest change being from intention for surgery to SRS being delivered.

SM Grading has proved to be an effective means of assessing the likely morbidity/mortality associated with surgical intervention for any given bAVM. Spetzler et al. (Lawton et al., 2010) published a 3-tiered management grading based on the SM grade – Class A (SM Grade I and II) should be offered surgical resection, Class B (SM Grade III) should be offered multimodality treatment and Class C (SM Grade IV and V) should only be offered treatment if there is evidence of progressive neurological deficit or aneurysms that are identified on surveillance angiogram, due to the high risk of mortality and morbidity.

13.62 % (102) patients with ruptured bAVMs underwent surgery, as compared to 24.27 % (234) in the unruptured group. These results suggest that within the UK & Ireland neurosurgical community, the findings of the ARUBA study are not necessarily being adopted, and that surgery is still considered a relevant treatment option. With long term analysis including outcome data, such registry will give an opportunity to provide insights into a tailored approach for management of both ruptured and unruptured bAVMs.

The role of radiosurgery remains unclear, in SM Grade 4 and 5 bAVMs. An international multicentric trial (Patibandla et al., 2017) showed single-session SRS had limited efficacy in the management of these high grade bAVMs, with favourable outcomes noted in only a very small proportion of unruptured bAVMs. The data from this registry also reflects the low rates of treatment success including SRS for high grade bAVMs.

Whilst the registry provides insights into the treatments intended for bAVMs, the authors emphasise that this registry does not evaluate the reasons that underpin the choices of treatment. This will require a subsequent separate qualitative evaluation which will be an adjunct to

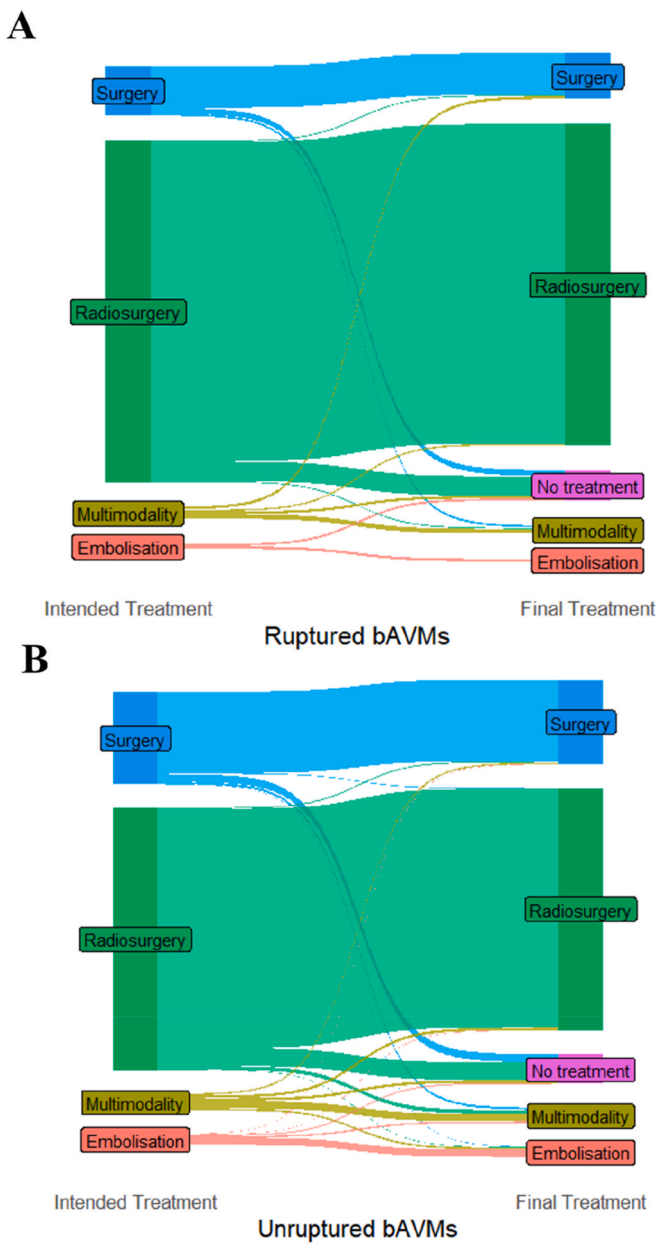


**Fig. 6.** Sankey plots the intended treatment and final management instituted across ruptured (A) and unruptured (B) bAVMs.

**Table 2**
Distribution of SM Grade (ruptured versus unruptured).

| SM Grade | Ruptured | | Unruptured | |
|---|---|---|---|---|
| | n | % | n | % |
| 1 | 113 | 15.63 | 157 | 17.12 |
| 2 | 332 | 45.92 | 365 | 39.80 |
| 3 | 196 | 27.11 | 316 | 34.46 |
| 4 | 78 | 10.79 | 71 | 7.74 |
| 5 | 4 | 0.55 | 8 | 0.87 |

the data presented, but at present the data does shed some light into the decision making. The group evaluated how age affected the choice of treatment. The decision to recommend SRS did appear to be influenced by age, with relatively consistent results across the age groups. Due to the relatively less invasive nature of the SRS, patients who may be frail or have multiple medical comorbidities would not necessarily be

**Table 3**
Distribution of Treatments Across SM Grades (Percentages reflected are for the unruptured/ruptured/total group).

| SM Grade | Radiosurgery | | | Surgery | | | Embolization | | | Multimodality | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Ruptured | Unruptured | Total | Ruptured | Unruptured | Total | Ruptured | Unruptured | Total | Ruptured | Unruptured | Total |
| 1 | 75 (66.37) | 82 (52.23) | 157 (58.15) | 34 (30.09) | 63 (40.13) | 97 (35.93) | 1 (0.88) | 3 (1.91) | 4 (1.48) | 3 (2.65) | 9 (5.73) | 12 (4.44) |
| 2 | 281 (84.64) | 234 (64.11) | 515 (73.89) | 44 (13.25) | 108 (29.59) | 152 (21.81) | 1 (0.30) | 9 (2.47) | 10 (1.43) | 6 (1.81) | 14 (3.84) | 20 (2.87) |
| 3 | 174 (88.78) | 250 (79.11) | 424 (82.81) | 14 (7.14) | 41 (12.97) | 55 (10.74) | 4 (2.04) | 13 (4.11) | 17 (3.32) | 4 (2.04) | 12 (3.80) | 16 (3.13) |
| 4 | 68 (87.18) | 49 (69.01) | 117 (78.52) | 7 (8.97) | 11 (15.49) | 18 (12.08) | 0 (0) | 4 (5.63) | 4 (2.68) | 3 (3.85) | 7 (9.86) | 10 (6.71) |
| 5 | 4 (100) | 7 (87.50) | 11 (91.67) | 0 (0) | 1 (12.50) | 1 (8.33) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) | 0 (0) |

**Table 4**
SM Grade Distribution Based for bAVMs that had change in management from intended treatment.

| SM Grade | Ruptured bAVMs | | Unruptured bAVMs | |
|---|---|---|---|---|
| | n | % | n | % |
| **1** | 5 | 6.76 | 14 | 11.38 |
| **2** | 28 | 37.84 | 38 | 30.89 |
| **3** | 24 | 32.43 | 39 | 31.71 |
| **4** | 7 | 9.46 | 16 | 13.01 |
| **5** | 1 | 1.35 | 0 | 0.00 |
| **Unknown** | 9 | 12.16 | 16 | 13.01 |

**Table 5**
Distribution of AVMs Grades and Treatment based on Age.

| | Age equal or more than 70 | Age less than 70 |
|---|---|---|
| **Embolization** | 4 (2.99) | 37 (2.34) |
| **Multimodality** | 3 (2.24) | 58 (3.67) |
| **Radiosurgery** | 98 (73.13) | 1177 (74.54) |
| **Surgery** | 29 (21.64) | 307 (19.44) |

**Table 6**
Choice of treatment with age.

| Treatment Choice | Estimate | Std Error | p-value |
|---|---|---|---|
| Radiosurgery | 0.003 | 0.003 | 0.315 |
| Surgery | −0.005 | 0.003 | 0.103 |

*p < 0.05, **p < 0.01, ***p < 0.001.

excluded from treatment. The recommendation for surgery, decreased significantly for older patients. Concerns about anaesthetic risk, perioperative cardiovascular risk factors, immediate and long-term neurological outcomes are often deterrents to choosing surgery in elderly patients. Further analyses into long term outcomes would be required to understand if any subgroup of patients, despite their age, could still benefit from surgery.

### *4.1. Limitations*

The team recognises the limitations of the present study. Whilst the registry provides a valuable insight into the current treatments being offered for both ruptured and unruptured bAVMs, it is still highly dependent on data capture, and with a minority of eligible centres not able to provide data, the findings cannot be interpreted as reflecting the entire population. Despite the prospective nature of the registry, patients may be missed at various time points in their treatment journey, and coupled with the fact that not all neurosurgical centres are actively involved (19/24), means that we do not have a complete representation of treatment decisions for bAVMs. Currently, this phase of the registry does not provide information on technical morbidity, obliteration rates, or clinical outcomes but these are aspects in development, and will be useful in benchmarking practice and commissioning service, which are integral features of providing a high quality clinical service within the NHS.

The authors acknowledge that the reported data from this study pertains narrowly to treated bAVMs and those patients for whom treatment was intended rather than providing information from an observational perspective. The current registry has highlighted the issues that arise due to resource limitations and retrospective data entries. Whilst the registry has attempted to circumvent the problem by allowing both the referral centre and treatment centre to create/modify the data entries, this does not allow for population based analysis.

The authors also emphasise that theses analyses, are not intended as recommendations on the management of bAVMs but rather serve to provide an early insight intop the current treatments being offered for bAVMs, ruptured or unruptured across different specialist neurovascular units within UK and Ireland.

## 5. Conclusion

This initial report highlights the some of the challenges of setting up, a national bAVM registry, even when with a narrow focus on just the treatments beingundertaken but does also show that this is feasible and can provide valuable comparative data, allowing subsequent iterations of the Registry to collect more complex data on technical morbidity and clinical outcomes.

## Declarations

**Human Ethics and Consent to Participate declarations: not applicable (Please refer below for details).**

Each centre that participated in this study obtained their local ethics approval for data collection (institutional research ethics committee) in accordance with the 1964 Declaration of Helsinki and its later

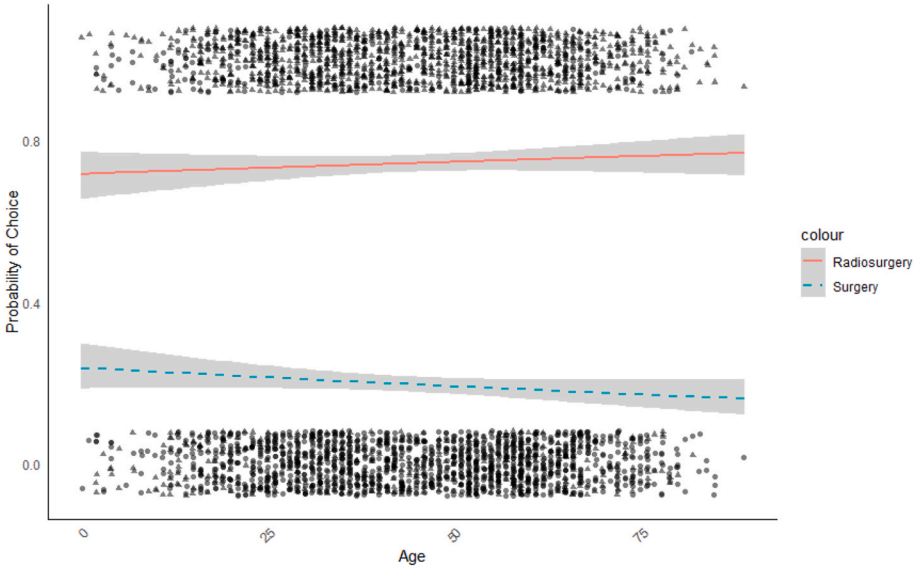


**Fig. 7.** Probability of choice of SRS and surgery with age.

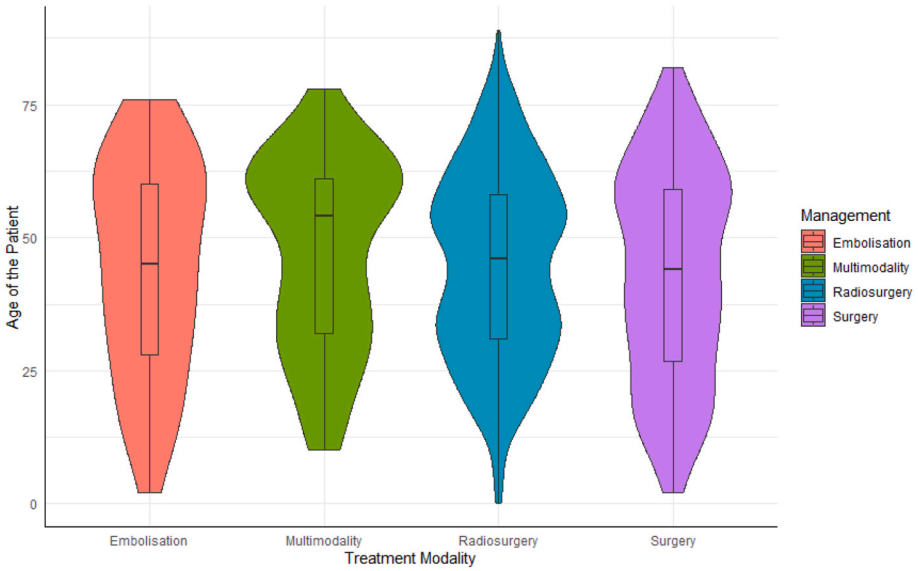


**Fig. 8.** Violin plots for different treatment options and the patient's age.

amendments. All patients were consented at the time of their presentation for their data to be added to the registry. However, analysis of the registery did not require any further ethics or approval by institutional review board. The registry was formulated as part of standard clinical practice for audit and clinical governance. In keeping with the trust guidelines, no formal ethics approval was required for analysis and presentation of this data.

## Funding and disclosures

All authors have no disclosures, including any related to funding for the purposes of this study.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.bas.2025.105868.

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