

VASCUNET REPORT

Editor's Choice – Vascular Registries Contributing to VASCUNET Collaborative Abdominal Aortic Aneurysm Outcome Projects: A Scoping Review

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WHAT THIS PAPER ADDS

The VASCUNET collaboration benefits from international efforts to leverage real world data from multiple vascular surgery registries. The mutual goal has been to report on procedural and early outcomes to drive audit and promote quality improvement and patient safety. Outside of the VASCUNET collaboration, less is known about the attributes of the individual registries. This paper aimed to provide a summary and to encourage transparency of participating VASCUNET registries in the abdominal aortic aneurysm (AAA) collaboration. Increased awareness of its proficiencies and limitations should improve future analyses and collaborations. Moreover, it should provide guidance and reference for new registries that may wish to join the VASCUNET collaboration.

Objective: Vascular surgery registries report on procedures and outcomes to promote patient safety and drive quality improvement. International registries have contributed significantly to the VASCUNET collaborative abdominal aortic aneurysm (AAA) outcome projects. This scoping review aimed to outline the national registries in vascular surgery that currently participate in the VASCUNET collaborative AAA projects.

Methods: A scoping review of all published VASCUNET AAA studies and validation reports between 1997 and 2024 was undertaken. A survey was conducted among representatives of the international vascular registries contributing to VASCUNET collaborative AAA projects.

Results: Currently, vascular registries from 10 countries (Australia, Denmark, Finland, Hungary, Iceland, New Zealand, Norway, Sweden, Switzerland, and the UK) contribute to the current VASCUNET collaborative AAA project, of which eight have national coverage. In the past, three countries (Germany, Malta, and Italy) have participated in previous VASCUNET AAA projects, and a further three countries (Serbia, Greece, and Portugal) have planned participation in future projects. External validity is high for all current registries, with most reporting rates of > 90%. The majority have internal validation processes to assess data accuracy. VASCUNET mediated validation has also been performed by the consortium for five countries to date (Hungary, Sweden, Denmark, Malta, and Switzerland), for which a high degree of external and internal validity was identified. Most registries have established mechanisms for data linkage with national administrative datasets or insurance claims datasets and contribute to quality improvement through regular reporting to participating centres.

Conclusion: National vascular registries from nations participating in the VASCUNET collaborative AAA projects are largely comprehensive, with high case ascertainment rates and good quality data with internal quality assurance. This provides a template for new registries wishing to join the VASCUNET collaboration and a benchmark for future research.

[†] A list of the VASCUNET AAA Registry Collaborators is included in [Appendix A](#).

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INTRODUCTION

Continuous evaluation of abdominal aortic aneurysm (AAA) repair outcomes on centre, regional, and national levels is of value to ensure that surgical practice, which may vary, provides overall benefit at an equivalent standard. As such, the European Society for Vascular Surgery (ESVS) advised the implementation of structures to enable ongoing monitoring of AAA repairs.¹ At a local level, independent assessment of the quality of care can be challenging, as AAA repair can be a high risk prophylactic procedure, with wide variation in surgical volumes. One solution is the use of dedicated vascular registries, which are designed to report on AAA repair and to drive quality improvement, with further scope for international comparisons.¹

VASCUNET is a collaboration of European and Australasian vascular surgeons dedicated to quality improvement through health service research (<http://www.vascunet.org>).² International registries have contributed significantly to VASCUNET collaborative AAA outcome projects.³ The power of international benchmarking and feedback to generate quality improvement was demonstrated when a disparity in mortality following AAA repair between the UK and eight other countries was identified.^{4,5} Subsequent quality improvement efforts from the UK Vascular Services Quality Improvement Programme (VSQIP) were accompanied by a 5.1% decrease in mortality rate for elective AAA repair.⁶

Assessment of data quality in registries is of the utmost importance. Correctness of the entered data (i.e., *internal validity*) and completeness of registration of procedures (i.e., *external validity*) within the region covered should be checked routinely. In addition to various national solutions, VASCUNET offers mediated validation of national registries and carries out both types of data quality assessment.⁷

This scoping review aimed to outline the national registries in vascular surgery that currently participate in the VASCUNET collaborative AAA projects. The review was prompted by reviewers' comments on the quality of data from vascular registries in previous and current projects. This will provide a basis for reviewing datasets across established registries and a template for countries that do not have an established registry. It will also provide a benchmark for audit, quality improvement, and research projects to drive patient safety and improve outcomes. It may encourage participation from currently non-participant nations in future VASCUNET collaborative AAA projects.

METHODS

This was a scoping review aiming to present key information on the national vascular registries contributing data to VASCUNET.⁸ This included the scope of national coverage, reported external and internal validity, duration of the registry, ability to link to national datasets, and a weblink to

provide further information. In addition, basic information on the healthcare system of each country with a participating vascular registry was collected and presented.

Information was obtained from all published VASCUNET reports on AAA or registry validation as well as from unpublished validation reports and the latest annual reports of the participating registries. Published VASCUNET reports on AAA or registry validation reports were reviewed for the period since the foundation of VASCUNET in 1997 until the end of 2023. In addition, representatives from each international clinical vascular registry contributing to the VASCUNET collaborative AAA project were contacted and asked to provide information regarding their registries.

Survey among registry representatives

A questionnaire was developed and pre-defined by the VASCUNET AAA working group as part of the current AAA project being led by an author (A.D.P.) and in response to reviewers' comments on the previous AAA study.³

The survey included items on the registry duration and coverage and on the current process of data quality assurance, as well as information of data linkage. Quality assurance included means to assure *internal validity* (e.g., accuracy of data entered for specific procedures in specific hospitals compared with hospital records) as well as *external validity* (e.g., the completeness of the recording of all patients treated in certain hospitals).⁹ Furthermore, representatives were asked to state the methods of reimbursement for inpatient procedures (i.e., population based, diagnosis related group [DRG] fee for service, or insurance claims based) and whether a national AAA screening programme and a national independent AAA quality improvement programme was established in their countries.

Of the 26 nations in the VASCUNET committee, questionnaires were sent out to VASCUNET representatives from 18 nations who have participated in or expressed an interest in participation in AAA projects (Table 1). Responses were received from all 18 countries, of which two did not have national registries, and all were included in the analysis.

Data from responses were cross validated with the available information from VASCUNET publications as well as registry reports by two authors (A.L.P. and L.M.). Identified discrepancies were clarified with the original respondent and the VASCUNET AAA working group.

The information was summarised descriptively in a table. For the reported validity measures (i.e., external and internal validity) two sided 95% confidence intervals (CIs) were calculated if these were not reported in the original reports.¹⁰ The minimum required information to calculate single proportion 95% CIs is a denominator and numerator of the reported proportion. The calculations were conducted using R version 4.2.3 on macOS 12.5.1

Table 1. Summary of abdominal aortic aneurysm (AAA) registries within the VASCUNET AAA project.							
Registry/ country	Duration	Estimated coverage for AAA	Internal validation for AAA *	External validation for AAA *	Data linkage	AAA screening	QIP
AVA, Australia ¹⁶	2010–present	Nationwide, compulsory ³³	97.4% (96.9 –97.8 [#]) Validation every 3 y (2010 –2012) ³³	62.3% (61.1 –63.4 [#]) Annual validation (2010 –2012) ³³	No	No	Reporting only
AVA, New Zealand ¹⁶	2010–present	Nationwide, compulsory (neither administrative nor registry data complete)	~56.8% (54.5–59.1 [#]) to 99.7% (99.3–99.9 [#]) depending on variable (2015 –2019) ^{31,32}	~80.2% (78.6–81.8 [#]) (2015 –2019) ^{31,32}	Yes, linked to national registry of deaths	No	Reporting only
Dansk Karbase, Denmark ²⁰	1993–present	100% intact and ruptured AAA	97.4% (95.4 –98.8) (2016) ⁷ VASCUNET validation	98.4% (97.1 –99.2 [#]) Annual check against LPR (2016) ⁷ VASCUNET validation	Linked to LPR	No	Monthly reporting of regional quality indicators
German AAA registry ²⁵	1997–present	40–50% of centres 20–30% of AAA repairs	No	No	Available linkage specific to health insurer	Yes	Yes
HEVAR, Greece	2019–present	~20–30%	No	No	No	No	No
Hungarian Vascular Registry, Hungary ¹⁸	2002	95% for open repair; 100% for EVAR	Few discrepancies (2010) ²² VASCUNET pilot	99.3% (97.5 –99.8 [#]) (2010) ²² VASCUNET pilot	No	No	Reporting only
HUSVASC, Finland	2000– present †	35% of Finland (Uusimaa region only)	No	100% automated capture of all AAAs	Linked to national registry of deaths	No	Reporting only
Isvasc, Iceland	2008–present (subregistry to Swedvasc)	99% for AAAs	No	No	Linked to national registry of deaths	No	Reporting only
MaltaVasc, Malta ¹⁷	2009–present	100%	100% (2017 –2018) ¹⁷ VASCUNET validation	94.1% (84.1 –97.8 [#]) (2017 –2018) ¹⁷ VASCUNET validation	Linkage with national datasets	May 2022 –present	Reporting only
NORKAR, Norway	1996, national coverage 2009 –present. Digital since 2015	92% for AAAs (2021)	No	Annual against NPR at individual level	NPR at individual level and national registry of deaths	Local programme in Oslo only since 2011 ⁴³	NORKAR and Norwegian Vascular Society have defined quality indicators for treatment of AAA
NVR, UK	2013–present (commissioned by HQIP)	92–95% for AAAs	Annual national with HES data	Annual national	Linkage with HES/ONS	NAAASP 2013 –present. Men >65 y ⁴²	AAA QIP 2012 –present

Continued

Table 1-continued

Registry/ country	Duration	Estimated coverage for AAA	Internal validation for AAA *	External validation for AAA *	Data linkage	AAA screening	QIP
RNPV, Portugal ²⁶	2019–present	>90% of centres	No	No	No	No, pilot study, 2019 ⁴⁹	Each participating centre can analyse results against national benchmarking
SicveReg, Italy	2006–present	Unknown	No	No	Unknown	No, pilot study 2015 –2019, Teramo, Italy ⁴⁸	Unknown
SerbVasc, Serbia	2020–present	~70%	No	No	No	No, pilot conducted in March 2023 ⁴⁶	No
Swissvasc, Switzerland	1997–2016, 2018–present (digital)	80–90% for AAAs	VASCUNET 2023	>99%, VASCUNET 2023	No	No, pilot conducted in 2013 ⁵⁰	Since 2021, each unit receives an annual report on quality and national benchmarking
Swedvasc, Sweden	1987	~100% since 1994	96.2% (94.9 –97.2) (2012) ³⁴ VASCUNET validation and annual national	98.8% (96.9 –99.5) (2012) ³⁴ VASCUNET validation and annual national ³⁴	Linked to national registry of deaths, other linkage possible	SNAASP 2006. National since 2015 –present. Men >65 y ⁴¹	Each unit receives regular reports on quality

AAA = abdominal aortic aneurysm; AVA = Australasian Vascular Audit; EVAR = endovascular aneurysm repair; HES = Hospital Episode Statistics; HEVAR = Hellenic Vascular Registry; HQIP = Healthcare Quality Improvement Partnership; HUSVASC = Finnish Vascular Registry; LPR = Landspatientregisteret/national healthcare registry; NAAASP = National Abdominal Aortic Aneurysm Screening Programme; NORKAR = Norwegian Vascular Surgery Registry; NPR = National Hospital Episode Statistics; NVR = National Vascular Registry; ONS = Office for National Statistics (registry of deaths); QIP = quality improvement programme; RNPV = Portuguese National Registry of Vascular Procedures; SicveReg = Registry of the Italian Society for Vascular and Endovascular Surgery; SNAASP = Swedish Nationwide Abdominal Aortic Screening Programme.

* Summary of information of national vascular registries as extracted from validation reports and stated by national representatives. Information on internal and external validity were presented with the period of validation (in parentheses) and reflect information reported for AAA. Calculated 95% confidence interval based on the published proportion are indicated by #.

† FINNVASC (Finnish Vascular Registry) had national coverage from its establishment in 1989 until 2000 and was continued thereafter as HUSVASC only covering the central region Uusimaa.

(Vienna, Austria: R Foundation for Statistical Computing; <https://www.R-project.org/>). No formal statistical comparison of the reported key figures was carried out in this scoping review.⁸

RESULTS

Vascular registries from 10 countries contribute to the current VASCUNET collaborative AAA project (Australia, Denmark, Finland, Hungary, Iceland, New Zealand, Norway, Sweden, Switzerland, and the UK) with data on procedures and short term outcomes (Table 1).¹¹ Of note, eight are national registries, Iceland is a subregistry of Swedvasc, and Finland has a regional registry. In addition, three countries (Germany, Malta, and Italy) have previously participated in AAA projects.^{3–5,11,12} Additional countries with newer reg-

istries, including Serbia, Greece, and Portugal, have confirmed participation and expressed interest in future AAA project involvement. France and Spain have participated in some VASCUNET collaborative AAA projects but do not currently have a national vascular registry.

The Swedvasc registry (<https://www.swedvasc.se>) was the first national registry in vascular surgery, established in 1987 and reaching national coverage in 1994.^{13,14} The Swissvasc registry (<https://swissvasc.ch/>) was founded in 1997; however, a complete relaunch was performed in 2016, and data are available from 2018 onwards, as old and new data were not merged due to incongruencies. NORKAR, the Norwegian Vascular Surgery Registry (<https://stolav.no/fag-og-forskning/medisinske-kvalitetsregistre/norkar>), was established in 1996 but did not obtain official status until

2009, and a web based solution was established in 2015.¹⁵ The Australasian Vascular Audit (AVA) (<https://www.anzsvs.org.au/audit/>), founded in 2010, provides coverage for Australia and New Zealand.¹⁶ Isvasc (Iceland Vascular Registry) has functioned as a subregistry to Swedvasc since 2008. The Dansk Karbase (Danish Vascular Registry) (<http://karbase.dk>) commenced in 1993, MaltaVasc (Maltese Vascular Registry) in 2009, the HUSVASC registry (regional Helsinki area alone, Finland) in 2000, and the Hungarian Vascular Registry (<https://vr.gokvi.hu/>) in 2002.^{7,17–20} The UK National Vascular Registry (NVR) (<http://www.vsqip.org.uk>) commenced in its present form in 2013, commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).⁶ It was preceded by the National Vascular Database (NVD), which was initiated by a group of enthusiasts in 1997 and run by the Vascular Society of Great Britain and Ireland (VSGBI).²¹ The German AAA registry was established in 1997, and in 2008 the German Institute of Vascular Research (DIGG) of the German Society for Vascular Surgery and Vascular Medicine (DGG) was implemented to maintain all vascular registries and research projects in Germany. The Italian registry (SicveReg) (<https://www.sicvereg.it/>) was established in 2006. The Hellenic Vascular Registry (HEVAR) (<http://vascularregistry.gr/registry>) and the Serbian Vascular Registry (SerbVasc) (<https://www.serbvasc.rs/>) were established in 2019. The AAA module of the Portuguese National Registry of Vascular Procedures (RNPV) (<https://spacv.org/>) was established by the Portuguese Society of Angiology and Vascular Surgery (SPACV) in 2019.

Scope of national coverage

Of the 14 vascular registries, eight provide current national coverage. The UK NVR has coverage across all four nations (England, Wales, Scotland, and Northern Ireland). The Hungarian Vascular Registry covers approximately two thirds of the population, but owing to centralisation of AAA services covers all AAA repairs nationally.²² The Swissvasc registry is voluntary, except in two regions, while 80 – 90% of aortic procedures (depending on the intervention) are covered by the registry.²³ The Swedvasc registry covers > 95% of all aortic procedures performed nationally.¹⁴ In Finland, between 1989 and 2000, national coverage was provided by FINNVASC. Following its termination, the HUSVASC registry covers the Uusimaa region incorporating Helsinki only, comprising approximately 35% of the population.^{12,24} The German AAA registry covers 20 – 30% of the annual procedures and 40 – 50% of the approximately 500 centres where AAAs are treated, with increasing participation since 2018.²⁵ In Italy there are approximately 130 hospitals that provide vascular surgical services and it has not been possible to accurately ascertain the extent of national coverage. Greek HEVAR is available for public and private hospitals and covers approximately 20 – 30% of AAA procedures. The SerbVasc registry covers 21 hospitals representing approximately 70% of national coverage. The

Portuguese registry has voluntary participation for > 90% of vascular centres.²⁶

There is currently no dedicated clinical registry for vascular surgery in France. However, since 2016 the French National Information System (Système National des données de santé [SNDS]; <https://www.snds.gouv.fr/SNDS/Accueil>) allows retrospective extraction of standardised Hospital Episode Statistics (HES) on all patients over a 10 year period. There is currently no clinical registry for vascular surgery in Spain.

Data linkage to healthcare datasets

Linkage to national healthcare datasets is not available for all registries. Most registries (e.g., HUSVASC, Isvasc, Swedvasc, UK NVR) have linkage to their respective national registry of deaths. The UK NVR is also linked to HES data. More comprehensive linkage is available for the Dansk Karbase – linked to the LPR (Landspatientregisteret/national healthcare registry); NORKAR – linked to the NPR (National Hospital Episode Statistics); and MaltaVasc, which uses a unique national identity number across administrative systems. Based on the personal identifiers, additional cross matching to other national registries in Sweden is possible, pending adequate ethical and regulatory approval.¹⁴ The AVA routinely uses de-identified national data, but direct patient level linkage can also be achieved at a significant cost.²⁷ In Switzerland, due to data protection restrictions, linkage to national data is currently unavailable. The Hungarian Vascular Registry, HEVAR, and SerbVasc do not have available linkage. In Germany, publicly available HES cover > 90% of inpatient procedures but do not allow longitudinal linkage to reveal complete comorbidities. While longitudinally linked patient specific data are available from several health insurers, they only cover patients insured by the respective health insurer. To generate population based, age and sex standardised estimates, a common database of comorbidities is available by the joint health insurance funds. In Italy, national data are controlled by AGENAS (National Agency for Regional Health Services and National Outcome Program), which has links with SICVE (Italian Society for Vascular and Endovascular Surgery). Information on national datasets and linkage was unavailable for Portugal. Although most registries collect mortality data at 30 days or in hospital, definitions and collection of further variables are heterogeneous, leading to challenges in interpretation of these data.³

Coverage of vascular registries

External validity is high for all registries with nationwide coverage in this report, with most reporting rates of > 90%.^{28,29} The highest rates of external validity were reported in Denmark and Finland (100%), secondary to use of automatic data capture from electronic healthcare records.⁷ The lowest reported external validity for an AAA registry participating in the VASCUNET collaborative AAA project was for Australia, which captured 65% of intact and 71% of ruptured open AAA repairs.³⁰ New Zealand, which also feeds data into the AVA, recently conducted a five year

validation (2015 – 2019) and presented an 80.2% external validity.^{31,32} Since 2016, completeness of NORKAR registrations is assessed annually against the Norwegian HES at an individual patient level, reaching 92% for AAAs in 2021.¹⁵ The UK NVR published annual external validation figures are consistently > 90%.²⁹

Quality assurance of vascular registries

There are different approaches to assessing data accuracy. The Swedvasc registry steering committee performs annual validations with evaluation of data against the national patient registry for external validity, as well as internal assessment processes. Swedvasc is also cross matched against the Swedish population registry using unique personal identifiers, which allows for 100% follow up for survival.¹⁴ However, its subregistry, Isvasc (Iceland), is not subject to the same validation process. The UK NVR assesses the consistency of data entered against HES data on an annual basis.²⁹ Internal validation of the AVA is conducted via random verification of a proportion of major arterial cases.^{31–33} The German AAA registry has not yet been externally validated, but it undergoes regular statistical assessment. HEVAR and SerbVasc are not yet validated. Validation was undetermined for the Italian registry and has not been undertaken within the Portuguese registry.

VASCUNET mediated registry validation addresses this heterogeneity in data quality assessment and provides a standardised validation process.⁹ To date, registries in five countries have been officially validated.^{7,9,17,22,34} The Hungarian Vascular Registry was the first assessed as a VASCUNET pilot project in 2012. A review of 29 selectively chosen patient records revealed > 94% external validity and few discrepancies on internal validity checks.²² In 2015, assessment of Swedvasc revealed 98.8% (95% CI 96.9 – 99.5%) external validity and 96.2% (95% CI 94.9 – 97.2%) internal validity.^{34,35} In 2019, evaluation of Dansk Karbase reported 98.4% external validity and 97.4% (95% CI 95.4 – 98.8%) internal validity.⁷ In 2020, evaluation of the Maltese MaltaVasc registry reported 97% external and 100% internal validity.¹⁷ Evaluation of the Swissvasc registry demonstrated > 99% external validity and few discrepancies on internal validity checks.⁹ A VASCUNET mediated validation of the UK NVR was arranged in 2020 but had to be deferred due to the COVID-19 pandemic; it is now planned for 2025.

Quality improvement programmes

Pathways for quality improvement are variable. The UK developed a national AAA quality improvement programme 2009 – 2012 to address the inferior results reported in the 2008 VASCUNET report,⁵ which set targets for delivery and outcomes for AAA repair.⁶ Other registries have also developed quality improvement programmes in different fields.^{36,37} NORKAR and the Norwegian Vascular Society have defined quality indicators for AAA repair, which were met for 87% of AAA patients in 2022.³⁸ For most other countries, registries provide annual (or more regular) reporting to participating centres as a mechanism for

quality improvement. In Switzerland, each participating unit receives an annual report with information about their centre and national benchmarking. For one greater area (~20% of the country) an annual quality round is carried out.³⁹

Abdominal aortic aneurysm screening

Current ESVS guidance on the management of AAAs recommends ultrasound based population screening for AAA in men aged 65 years (class I, level A).⁴⁰ Screening is implemented in several VASCUNET collaborative AAA project countries for 65 year old men, but not women. In Sweden, screening for AAA commenced in 2006 and achieved national coverage in 2015.⁴¹ The UK have implemented a National Abdominal Aortic Screening Programme since 2013.⁴² A local programme in Oslo (Norway) has used AAA screening since 2011.⁴³ Since 2017, a nationwide programme in Germany provides one time ultrasound based screening for all men aged > 65 years.⁴⁴ Malta commenced national AAA screening in May 2022.⁴⁵ The Serbian Society for Cardiovascular Surgery and Ministry of Health conducted a national pilot screening campaign for early AAA detection.⁴⁶ Denmark does not have an AAA screening programme but conducted a five year trial on cardiovascular screening that included AAA.⁴⁷ Pilot studies have also recently been conducted in Portugal, Italy, and Switzerland.^{48–50}

Methods of reimbursement for treatment of abdominal aortic aneurysms

Most countries with comprehensive nationwide vascular registries (Denmark, Finland, Hungary, Iceland, Malta, Serbia, Sweden, and New Zealand) use population based reimbursement. The UK largely uses a population based reimbursement model, with a few fee for service cases. Switzerland uses a DRG based fee for service, and Norway uses 60% population based reimbursement and 40% DRG based fee for service. Australia has both a public and fee for service based model, and Germany is insurance claims based with approximately 90% of patients being statutorily insured. Italy has a population based reimbursement model of care. In Greece, the fee for service within public hospitals is common and based on DRGs. Portugal has a fee for service model of care both in public and private hospitals.

DISCUSSION

VASCUNET is a collaboration of clinical and administrative vascular registries administered and partly funded by the ESVS. In all, 26 different countries collaborate in research projects to improve the quality of healthcare internationally. Since 2014, VASCUNET has coordinated with the Vascular Quality Initiative (VQI) of the Society for Vascular Surgery (SVS) in the International Consortium of Vascular Registries (ICVR) (<https://www.mdempinet.net/icvr>).

Administrative data sources are designed for recording procedures and volumes based on standard International Statistical Classification of Diseases and Related Health

Problems, Tenth Revision (ICD-10) and National Clinical Coding Standards OPCS-4.9 coding to guide reimbursement. There is no validation of administrative datasets, they lack granularity in terms of key parameters such as AAA size at treatment, and are limited by coding specifications, hence are more difficult to use for risk stratification.⁵¹ Randomised controlled trials for AAAs have limited utility for the guidance of real world patients owing to the narrow recruitment and treatment specifications as well as significant participant cross over, and require substantial cost and time to complete.⁵² In contrast, registries use large unselected cohorts, collect relevant parameters, and enable timely appraisal of trends in treatment and outcomes, at relatively low cost.^{1,3,12,53} Therefore, the level 2 real world evidence that registries provide augments randomised controlled trial data, enabling a more nuanced understanding of best practice for AAA repair.⁵⁴

There are, however, aspects of registry data capture that can be improved. The need for consensus regarding variable definitions and data collection was already recognised when VASCUNET was created in 1997, and the harmonisation project has been an ongoing process ever since. Furthermore, the quality of the data entered in the registries (internal validity) and the completeness of the recording (external validity) must be maximised, preferably using automated linkages. Besides these implemented strategies to enhance registry data quality, periodic validation of registries by independent authorities remains important. The role of VASCUNET mediated validation of participating vascular registries will be further promoted.^{9,19} Historically, the VASCUNET mediated registry validation process was not fully standardised, leading to an inconsistent validation process for different registries. A recently published VASCUNET template for registry validation should help to harmonise and standardise the validation process and thereby reduce potential sources of bias.⁹

A publication from the UK-COMPASS investigators in a recent issue of this journal highlights both the limitations of linking registry data (NVR) with administrative data (HES) and the limitations of coding of conditions of the juxtarenal aorta.⁵⁵ The investigators had to exclude 19.9% of patients ($n = 548$) from the analysis, and this was most likely due to missing National Health Insurance (NHS) numbers in patient NVR records that prevented linkage with HES datasets. There are several reasons for omission of the NHS number, which include errors in data entry, lack of consent, and patient's expressed desire to opt out of national NHS data schemes for research.⁵⁶ This has obvious implications, reducing the external validity and excluding some patients from analyses of registry data.^{11,29}

Another important limitation of AAA registry data is the failure to collect data on patients for whom a surgical repair is not offered, as differences in selection and treatment regimen may partially explain differences in treatment outcomes. This applies for asymptomatic AAAs as well as for patients with ruptured AAA who are turned down.⁵⁷

Further barriers to the successful implementation of a vascular registry include implementation of data privacy compliant systems. In 2018, the European Union (EU) General Data Protection Regulation (GDPR) came into force, introducing a major challenge for real world evidence research and data processing outside Europe. While several aspects of innovative data processing as well as data driven research were eventually consistently regulated in all EU member states, this new regulation also precluded the processing of personal health data outside EU law. Hence, since 2020, free flow of data between EU and US organisations is no longer lawful, which has had a massive impact on transatlantic research collaborations.^{58,59}

There is some argument that due to recent advances in the use of digital technology in healthcare services, the subsequent ability to analyse big data may redefine the roles of vascular registries.⁵⁴ Reimbursement models also impact the ability of registries to collect comprehensive national data due to segregation of information management systems. However, clinicians may be reluctant to enter data on independent sector patients, which are associated with divergent healthcare practice, for example increased endovascular aneurysm repair, in younger patients at lower size thresholds.¹² Another limitation of international registries is the inability to capture long term outcomes. As seen in numerous reports, capture of long term outcomes and re-interventions, with monitoring of safety and durability of implanted medical devices, will play an increasingly important role. The responsibility for capturing and reporting of these data to improve patient safety and allow device specific monitoring should fall on the registries.^{60,61}

Conclusion

National vascular registries participating in the VASCUNET collaborative to AAA projects are largely comprehensive, with high case ascertainment rates and excellent data accuracy. Greater unification of practices may enable more meaningful acquisition and amalgamation of these data, increasing the potential impact on patient safety. This provides a model for new registries wishing to join the VASCUNET collaboration and a benchmark for future research.

CONFLICTS OF INTEREST

None.

FUNDING

None.

APPENDIX A. SUPPLEMENTARY DATA

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ejvs.2024.04.037>.

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