



<http://www.diva-portal.org>

This is the published version of a paper published in *BMJ Open*.

Citation for the original published paper (version of record):

Eldh, A C., Wallin, L., Fredriksson, M., Vengberg, S., Winblad, U. et al. (2016)
Factors facilitating a national quality registry to aid clinical quality improvement: findings of a
national survey.

BMJ Open, 6(11): e011562

<http://dx.doi.org/10.1136/bmjopen-2016-011562>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:du-23428>

BMJ Open Factors facilitating a national quality registry to aid clinical quality improvement: findings of a national survey

Ann Catrine Eldh,^{1,2} Lars Wallin,^{2,3} Mio Fredriksson,¹ Sofie Vengberg,¹ Ulrika Winblad,¹ Christina Halford,¹ Tobias Dahlström¹

To cite: Eldh AC, Wallin L, Fredriksson M, *et al.* Factors facilitating a national quality registry to aid clinical quality improvement: findings of a national survey. *BMJ Open* 2016;**6**:e011562. doi:10.1136/bmjopen-2016-011562

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2016-011562>).

Received 26 February 2016
Revised 21 June 2016
Accepted 31 August 2016



CrossMark

For numbered affiliations see end of article.

Correspondence to

Dr Ann Catrine Eldh, anncatrine.eldh@pubcare.uu.se

ABSTRACT

Objectives: While national quality registries (NQRs) are suggested to provide opportunities for systematic follow-up and learning opportunities, and thus clinical improvements, features in registries and contexts triggering such processes are not fully known. This study focuses on one of the world's largest stroke registries, the Swedish NQR *Riksstroke*, investigating what aspects of the registry and healthcare organisations facilitate or hinder the use of registry data in clinical quality improvement.

Methods: Following particular qualitative studies, we performed a quantitative survey in an exploratory sequential design. The survey, including 50 items on context, processes and the registry, was sent to managers, physicians and nurses engaged in *Riksstroke* in all 72 Swedish stroke units. Altogether, 242 individuals were presented with the survey; 163 responded, representing all but two units. Data were analysed descriptively and through multiple linear regression.

Results: A majority (88%) considered *Riksstroke* data to facilitate detection of stroke care improvement needs and acknowledged that their data motivated quality improvements (78%). The use of *Riksstroke* for quality improvement initiatives was associated ($R^2=0.76$) with 'Colleagues' call for local results' ($p<0.001$), 'Management Request of Registry data' ($p<0.001$), and it was said to be 'Simple to explain the results to colleagues' ($p=0.02$). Using stepwise regression, 'Colleagues' call for local results' was identified as the most influential factor. Yet, while 73% reported that managers request registry data, only 39% reported that their colleagues call for the unit's *Riksstroke* results.

Conclusions: While an NQR like *Riksstroke* demonstrates improvement needs and motivates stakeholders to make progress, local stroke care staff and managers need to engage to keep the momentum going in terms of applying registry data when planning, performing and evaluating quality initiatives.

INTRODUCTION

Systematic collection and analysis of performance data is a commended approach

Strengths and limitations of this study

- A survey providing novel insight into what facilitates clinical quality improvements with regard to quality registries.
- Represents a study with a good response rate, using a validated survey, from across almost all units' stakeholders in one of the largest registries on stroke worldwide.
- While national quality registries (NQR) are more common in countries like Australia, Sweden and the UK, the findings may be applicable to users of other medical registries.
- Representing a well-established NQR, findings from *Riksstroke* may not illustrate barriers in developing registries and/or their use in clinical practice.

for monitoring quality of care and identifying areas of improvement.¹ Many countries have thus introduced medical registries to improve healthcare quality.²⁻⁴ Sweden has an extensive track record of national quality registries (NQRs).⁵ Providing for individual-based data entries on particular diagnoses, treatment interventions and outcomes, NQRs offer opportunities to monitor and thus improve healthcare quality.⁶

The NQR on stroke, *Riksstroke*, represents a renowned diagnosis-based registry. It was established in 1994, and since 1998, all hospitals providing stroke care partake in the registry, including 25 000–26 000 unique care episodes each year.⁷ *Riksstroke* comprises the acute care following a stroke and follow-up at 3 and 12 months after discharge for each individual, including medical aspects as well as the multi-professional stroke care process. It currently contains over 450 000 stroke events, making it one of the world's largest stroke registries.⁷

While *Riksstroke* is said to provide opportunities for systematic follow-up and learning

opportunities,^{8 9} neither this nor other NQRs have proven to be the expected drivers of local quality improvement. The local focus is often on entering complete data, while local analysis and initiation of improvements by the data is less common.¹⁰ Thus, the most recent national subsidisation of NQRs is accompanied by the prospect that NQRs will aid facilitation of continuous quality improvement, cultivating effectiveness and balancing differences in quality of care between health providers.¹¹ However, the complete picture as to how and when NQRs contribute to or initiate such processes is pending. Internationally, factors such as registry coverage, methods for data collection and the definition of variables are still discussed and compared between national stroke registries. Furthermore, a recent review concluded that there is uncertainty about how NQRs on stroke feedback on the quality of care to hospitals or patients; there is also a lack of detail on how data from such registries are used in quality improvement.¹²

Previously, using Riksstroke as a case in a series of qualitative studies, we found barriers and facilitators for quality improvement within the registry itself and in the interplay between inner and outer stroke care contexts.¹³⁻¹⁵ Beyond particular stroke process projects, the use of Riksstroke was ambiguous and highly dependent on devoted professionals in stroke units and among stakeholders at the politicoadministrative level. While these studies provided a profound understanding, including a sample of stroke care in Sweden, a more comprehensive understanding of how an NQR like Riksstroke promotes quality improvement is needed. This study investigates what aspects of Riksstroke and healthcare organisations facilitate or hinder the use of registry data in clinical quality improvement.

METHODS

Survey development

This quantitative study is the second phase of an exploratory sequential design.¹⁶ Previous qualitative findings exposed several factors for further investigation: the organisation's context; the individuals involved in local NQR work; the stroke healthcare process; data registration; data analysis; and experiences applying the NQR for initiating change.^{13 14} From these studies and a literature review, we produced a national survey. The survey was in Swedish, but an overview of the content and structure is presented in English (see online supplementary file I). The complete survey can be obtained from the research team.

The preliminary survey was tested for content validity and response process validity in three phases in January through May 2014.¹⁷ Initially, the research team examined the content validity in a workshop. Second, another six healthcare researchers external to the team examined the survey's structure, content, layout and responses in individual think-aloud interviews.¹⁸ The

input prompted minor changes to the wording of questions and response options. Third, the survey was tested in its target population, including five NQR users from across Sweden, all in charge of the local work in their units using three similar NQRs. They were appointed for individual telephone interviews; at the start of each interview, respondents received the survey by email, in accordance with the planned distribution for the main study. They were prompted to respond to the survey and to think aloud on its structure, content and layout. The test resulted in minor changes regarding wording and a reordering of certain items.

The final survey was designed in a web survey program (LimeSurvey, V.1.90+) and comprised 50 questions organised in 7 sections: (A) Background information about the respondent; (B) Quality of care; (C) Data quality; (D) Organisational conditions; (E) The respondent's use of registry data; (F) The stroke unit's use of registry data and (G) Perceived value of the registry. We mainly used a Likert scale approach for the responses, with five alternatives ranging from 'Strongly Disagree' to 'Strongly Agree'. However, section B partly applied a five-alternative Likert scale ranging from 'Very Poor' to 'Very Strong', and section E partly applied a four-alternative frequency scale ranging from 'Never' to 'Often'. Each section included an opportunity to provide additional remarks in free text, and the survey program allowed for each section to appear consecutively.

Sampling and procedure

At each stroke unit, the survey was sent to: (1) the head of the clinic, (2) the physician(s) in charge of Riksstroke (or, if there were none, the physician in charge of the stroke unit) and (3) the registered nurse (s), licensed practical nurse(s) and/or medical secretary (if any) in charge of registering local Riksstroke data. To identify respondents, the national Riksstroke registry administration shared their inventory of all 72 hospital units providing stroke care in Sweden and the name and address of the contact person at each stroke unit. From this information, we identified potential recipients and obtained names and email addresses, including at least two and at most five individuals per stroke unit (mean 3.5).

The survey was distributed via email in September 2014. After 2, 3 and 4 weeks, respectively, corresponding reminders were sent to those who had not yet replied. A final reminder was sent after week 5 that included an opportunity to provide reasons for not partaking. Individual consent to participate was achieved by the voluntary completion and submission of the survey.

Independent and dependent variables

We identified sets of dependent and independent variables (indexes) by processing theoretical knowledge and clinical experience, including our previous qualitative studies,^{13 14} and a literature review; all indexes are outlined in online supplementary file II. Essentially, an

Table 1 Factor loadings

Index	Pattern matrix Item	Factor loadings (only loadings above 0.5 are shown)				
		1	2	3	4	5
Data quality and usefulness (Cronbach's $\alpha=0.88$)	9. Data from the registry are of high quality					
	10. Data from the registry capture the essential aspects of quality of care		0.85			
	11. Data from the registry are a useful tool for identifying improvement areas		0.66			
	12. Data from the registry enable reliable internal comparisons over time		0.52			
	13. Data from the registry enable reliable external comparisons with other organisations registering in Riksstroke		0.74			
Resources (Cronbach's $\alpha=0.73$)	7. I believe the care of our patients with stroke has sufficient resources to maintain a high quality					
	14. We have sufficient resources (eg, allocated time and competence) to enter complete mandatory data in the registry					-0.82
	15. We have sufficient resources (eg, allocated time and competence) to analyse data from the registry					-0.79
	16. We have sufficient resources (eg, allocated time and competence) to perform improvement work based on registry data					-0.59
Support from outer setting (Cronbach's $\alpha=0.79$)	25. I get the support I ask for from support functions at the hospital				0.79	
	26. I get the support I ask for from the county council (equivalent to region)				0.74	
	27. I get the support I ask for from a regional registry centre				0.72	
Management request for registry data (Cronbach's $\alpha=0.91$)	17. My manager (the manager I report to) calls for data from the registry	0.66				
	47. Our results in Riksstroke are called for by the department managers	0.83				
	48. Our results in Riksstroke are called for by the hospital's board of directors	0.99				
	49. Our results in Riksstroke are called for by the county council board (equivalent to region)	0.94				
Management involvement in registry-based quality improvement (Cronbach's $\alpha=0.80$)	18. My manager (the manager I report to) supports improvement work initiated by others based on registry data					-0.52
	19. My manager (the manager I report to) initiates improvement work based on registry data					-0.61
Included as single items	24. I get the support I ask for from my own department			0.54		
	30. It is simple to explain our department's results to colleagues and managers		0.59			
	46. Our results in Riksstroke are called for by the department's members of staff					
	8. I consider our results in Riksstroke to be...					
	28. I get the support I ask for from Riksstroke					
	29. It is simple to retrieve registry data		0.51			
	31. I am motivated to improve the stroke care we provide as a result of our results in the registry		0.65			

index was created as a dependent variable that depicted the healthcare unit's use of registry data as reported by the respondents (Cronbach's $\alpha=0.89$). The following indexes, serving as independent variables, were constructed to capture: Support from Outer Setting; Management Request for Registry Data; Management Involvement in Registry-based Quality Improvement; Data Quality and Usefulness, and Resources. In addition, a number of single questions (items 8, 24, 28, 29, 30, 31 and 46) were included as independent variables comprising: the unit's local results; support from the local department and the registry; simplicity of retrieving data from the registry and explaining the results to colleagues and managers; motivation and colleagues' interest in Riksstroke data.

Validation of indexes

A factor analysis was conducted using SPSS V.23 to validate that our indexes contained relevantly grouped individual items. The factors were first extracted using direct oblimin rotation. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.75, indicating that a factor analysis was appropriate for the material, while Bartlett's Test of Sphericity had a significance of 0.000, indicating that the data were appropriate for factor analysis. The highest correlation between our factors was 0.35, validating the use of the direct oblimin rotation. The scree plot suggested using four factors, but performing the exploratory factor analysis to validate our five indexes, we chose to extract five factors. The factor analysis generally validated our scales as seen in [table 1](#). The extracted factors had a high degree of correspondence with those constructed on theoretical bases a priori. As a final test, we calculated the Cronbach α (using SPSS, V.23) on our indexes, identifying a range from 0.73 for 'Data Quality and Usefulness' to 0.91 for 'Management Request of Registry Data'. Details are found in [table 1](#) and online supplementary file II.

Statistical analyses

A descriptive analysis of individual respondents' demographics and responses was conducted using SPSS V.23, dichotomising the items with a cut-off at Agree. A descriptive analysis of the independent variables used in the regression analysis was also conducted. Using STATA V.13, a multiple linear regression analysis was performed. The chosen unit of analysis was 'stroke unit' (not individual respondent) to avoid stroke units with more respondents having a larger impact on the results. Normal distribution of the residuals was verified (the sk-test and Shapiro-Wilk test) and the test for heteroscedasticity (the Breusch-Pagan test) could not reject constant variance. We used the forward selection criteria to determine the order of inclusion in the stepwise regression and then the nestreg command to determine the change in R^2 .

RESULTS

Response rate and demographics

The survey was sent to 242 individuals, 163 of whom responded (67%), representing 70 of the 72 Swedish hospitals with stroke units (97%). Most respondents were registered nurses, followed by physicians and managers and completed more than one task with Riksstroke, for example, data registration and data analysis (see [table 2](#)). A vast majority had been engaged with the local Riksstroke for 3 years or longer, indicating potential for experience with full annual cycles of reporting, feedback and analyses. Those who did not respond (but specified why) were mainly managers who reported not working with Riksstroke enough to respond to the survey.

Descriptive results

Aggregating the response alternatives 'Strongly agree' and 'Agree', most respondents felt Riksstroke provided data for identifying areas in need of improvement (88%) and reported using Riksstroke data to do so (76%). Slightly fewer, 63%, reported performing local analyses of their data in Riksstroke, but only 42% reported having enough resources, for instance, time and skills, in the stroke unit to analyse their data. Even with this potential lack of resources, 61% of respondents reported that they retrieve data and 68% that they participate in data analysis. A slight majority (59%) reported that their manager supports quality improvement based on their unit's data and still more (73%) that their managers request data from the registry. While

Table 2 Demographics of respondents

Type of demographics	Replies	Number (%) n=163
Sex	Women	119 (72.6)
	Men	43 (26.4)
Profession*	Physician	47 (28.8)
	Secretary	7 (4.3)
	Registered nurse	69 (42.3)
	Licensed practical nurse	13 (8)
	Manager	35 (21.5)
Role in the local work with Riksstroke	Other	17 (10.4)
	Local responsibility for the registry	52 (31.9)
	Entering data in the registry	71 (43.6)
	Collecting data for the registry	65 (39.9)
Number of years in this role	Manager	48 (29.5)
	Other	21 (12.8)
	>1 year	23 (14)
	1–2 years	30 (18)
	3–5 years	39 (24)
	6 years or more	71 (44)

*Multiple answers are possible.

Table 3 Descriptive results—details

Items, including their respective openings when appropriate		Number (per cent) agreeing (incl. Strongly agree and Agree) (n=163)*
I believe the care of our stroke patients...	Is of high quality	153 (94)
	Has sufficient resources to maintain a high quality	70 (44)
I consider our results in Riksstroke to be...†		124 (77)
Data from the registry...	Are of high quality	134 (83)
	Capture the essential aspects of quality of care	136 (84)
	Are a useful tool for identifying improvement areas	142 (88)
	Enable reliable internal comparisons over time	145 (89)
	Enable reliable external comparisons with other organisations registering in Riksstroke	126 (77)
We have sufficient resources (eg, allocated time and competence) to...	Enter complete mandatory data in the registry	88 (54)
	Analyse data from the registry	69 (42)
	Perform improvement work based on registry data	64 (40)
My manager (the manager I report to)...	Calls for data from the registry	102 (63)
	Supports improvement work initiated by others based on registry data	94 (59)
	Initiates improvement work based on registry data	67 (42)
I get the support I ask for from...	My own department	102 (65)
	Support functions at the hospital	39 (27)
	The county council (equivalent to region)	22 (15)
	A regional registry centre	24 (17)
	Riksstroke (the registry organisation)	110 (71)
It is simple to...	Retrieve registry data	93 (59)
	Explain our department's results to colleagues and managers	99 (63)
I am motivated to improve the stroke care we provide as a result of our results in the registry		99 (78)
I...	Retrieve registry data	99 (61)
	Partake in analysis of registry data	109 (68)
	Report registry results to others	126 (79)
	Suggest improvements to our stroke care by means of our results in the registry	127 (79)
	Participate in improvements in our organisation by means of our results in the registry	120 (70)
	Manage improvements in our organisation by means of our results in the registry	91 (58)
In my department, we...	Enter complete mandatory data in the registry for all eligible patients	150 (93)
	Use the registry indicators in our activity plan	105 (66)
	Perform own analyses of our data in the registry	99 63
	Use registry data to identify issues where there is a need to change	121 (76)
	Carry out the improvements which we have deemed necessary based on our results in the registry	109 (70)

Continued



Table 3 Continued

Items, including their respective openings when appropriate	Number (per cent) agreeing (incl. Strongly agree and Agree) (n=163)*
Regularly present our results in the registry to members of staff	93 (60)
Use registry data to compare our results to similar organisations	94 (59)
Use registry data when introducing new clinical methods and procedures	61 (39)
The department's members of staff	62 (39)
Our results in Riksstroke are called for by...	
Department managers	118 (73)
The hospital board of directors	101 (64)
The county council board (equivalent to region)	81 (54)
I believe that what we gain from partaking in the registry justifies the resources spent on working with it	104 (65)

*Missing responses, range 0–22 (mean 4.7).
†Item response alternatives ranging from 'very poor' to 'very strong', incl., including.

63% considered it simple to explain data to fellow staff and managers and 79% presented registry data to others, only 39% reported that their colleagues call for Riksstroke results from their unit. All details are represented in table 3.

Multiple regression results

Using the index of the healthcare unit's use of registry data as a dependent variable, three independent variables were found to be significant: one index 'Management Request of Registry Data' ($p < 0.001$), and two single items: 'It is simple to explain our department's results to colleagues and managers' ($p < 0.001$) and 'Our results are called for by staff members' ($p < 0.001$). These three variables explained 75% of the total variance ($R^2 = 0.75$). Neither data quality nor resources were found to be significant for the unit's use of Riksstroke for quality improvement (see table 4). Using stepwise regression, we could see that 'Our results are called for by Members of Staff' had the highest impact on explained variance, followed by the index 'Management Consideration of Data' (see table 5).

DISCUSSION

While quality registries are suggested as a vehicle for improving quality of care, the complete picture of how and when registries inform or drive these processes has not been fully appraised. Riksstroke is often employed in research¹⁹ and thus contributes to better care for patients with stroke. However, as with many healthcare innovations, it is not fully known if, how, where and when the NQR is applied in clinical practice²⁰ and what lies behind its effectiveness in improving care, although organisational factors are generally pointed out as important.²¹ In previous qualitative studies, we found that health professionals and decision-makers depicted contextual factors at the stroke unit, hospital and regional levels to affect the use or lack of use of Riksstroke to improve stroke care.^{13 14} Additional features were found in this study to further illustrate the application of Riksstroke in local quality initiatives. Primarily, the role of managers and coworkers will be considered, along with the limited support this study provides for the notion that resources and data quality shape quality improvement.

Besides research, local quality improvements are needed to advance healthcare. Access to local data is crucial for quality improvement.²¹ Our findings emphasise that recipients need to understand their local performance in conjunction with healthcare quality to capture improvement needs.²² While an NQR like Riksstroke can provide stroke units with opportunities to access their local longitudinal data on aggregated levels, and to benchmark their care to national standards and/or other stroke units,²³ feedback should be managed in groups of peers, with repeated communication on the data to feed improvement initiatives.²⁴ The registry can

Table 4 Regression results, multiple regression

Independent variables	Coefficient	p Value
Support from outer setting	-0.098	0.572
Management request for registry data	0.447	<0.001
Management involvement in registry-based quality improvement	0.009	0.976
Resources	0.160	0.272
Data quality and usefulness	-0.031	0.880
I consider our results in Riksstroke to be...	0.250	0.747
I get the support I ask for from my own department	-0.016	0.974
I get the support I ask for from the registry organisation	0.490	0.315
It is simple to retrieve registry data	-0.333	0.502
It is simple to explain our department's results to colleagues and managers	1.411	0.022
I am motivated to improve the stroke care we provide as a result of our results in the registry	-0.610	0.323
Our results in Riksstroke are called for by members or staff	2.642	<0.001
Constant	5.776	0.110
	N	70
	R ²	0.759

then function as a platform to improve outcomes by engaging physicians and other clinical staff in the shared task of improving the quality of care.²⁵

Although Sweden and other countries like Australia and the UK have invested in NQRs like Riksstroke,^{26 27} most efforts focus on securing data quality.^{13 14} For future progress, quality improvement initiatives must focus on enhancing improvement knowledge and skills, an assignment beyond stroke care expertise.²⁸ A comparison between Sweden and the USA suggests that the Swedish registries are prone to foster clinical quality improvement, given the accommodating regulations and resources provided at the national level. However, the US system with, for example, automated data capture allows resources to be spent on improvement initiatives, rather than data registration.²⁹ Registry expertise and experience shared across countries could stimulate further development in how to use comprehensive process and results data in improving, for example, stroke care.³⁰ In Sweden, one of the limitations of registries such as Riksstroke is evidently the burden of registering data.²⁹ This is most likely reflected in that merely 65% of the Riksstroke respondents considered the gain from partaking in the registry, justifying the resources spent on working with it. Implementing automatised data capture could shift resources from securing data to data-led quality improvement work; however, to facilitate clinical improvement, health professionals, managers and policymakers need further support and opportunities to engage in joint ventures.¹⁵

A closer look at the results reveals a complex picture: while neither data quality nor resources were significantly correlated with the use of NQR data in local quality improvement, more professionals involved in Riksstroke reported that they themselves use data to improve quality than their stroke unit using data for this purpose. The limited engagement from colleagues and the obvious influence of the use of data on local quality improvement suggests the image of a lone stroke expert deciphering local data, while the stroke team members are unaware of the opportunities for quality improvement at their fingertips. Local Riksstroke stakeholders aggregate and present data to peers and managers and find this rather simple. However, this does not seem to increase engagement from peers. Our previous study showed that staff members engaged in Riksstroke at the stroke unit level are aware of the need to identify unique selling points to involve their colleagues.¹³ However, more collaborative efforts and an understanding of quality improvement are necessary if the data are to help improve stroke care and not just provide feedback. Managers are often considered key to support clinical quality improvement,^{13 14 31} which our findings also support. However, our results show that peer support is just as important, if not more so, to keep up the momentum to improve stroke care based on an NQR like Riksstroke. This factor had the strongest association with the unit's use of Riksstroke data for quality improvement. The need for team collaboration and support among coworkers is congruent with findings from

Table 5 Regression results, stepwise regression

Inserted variable	Block	R ²	Change R ²
Our results in Riksstroke are called for by members or staff (item 46)	1	0.59	
Management request for registry data	2	0.71	0.12
It is simple to explain our department's results to colleagues and managers (item 30)	3	0.74	0.03

studies on quality improvement,³² suggesting that successful quality improvement is a joint effort and support from others is a motivating factor for facilitating improvement.³³ The importance of interplay between the adoption of innovations³⁴ by individuals and organisations further emphasises the motivating impact of others being engaged in the same issues as oneself. Improvements are social processes, and relationships and communication are thus significant for quality improvement. Leaders are important in quality improvement,³⁵ but locally appointed staff working with the registry apparently need staff members to engage to improve stroke care.

Methodological considerations

Sweden has a universal, comprehensive and tax-based healthcare system similar to those of larger nations like Australia, the UK and Canada. As a result, experiences with NQRs in Sweden may be relevant to registry initiatives in other countries. Riksstroke is a well-known and acclaimed registry, giving this study the potential to pinpoint factors that facilitate quality improvements to stroke care and other similar registries.

The match between the indexes constructed a priori and the factors identified in the factor analysis worked out relatively well. To facilitate the interpretation of the regression analysis, we chose to keep the theoretically constructed indexes instead of using the factor solution. Given our cross-sectional design, the results cannot distinguish between cause and effect. While we have not tested for causation, it is reasonable to believe that the identified associations are not unidirectional, but rather that there are feedback loops.

CONCLUSIONS

Previous studies have shown that besides being a rich source for research, an NQR such as Riksstroke can provide opportunities for local stroke care quality improvement. This study represents 97% of all stroke units across Sweden and a broad scope of managers, physicians and nurses involved in the local assignment with Riksstroke; we found that most participants considered Riksstroke to enable comparisons using relevant and reliable data, and resources spent on Riksstroke to be worthwhile. Yet, data analyses and quality improvements based on the data received less attention than the registration of data. In addition, the use of Riksstroke data for quality improvement initiatives was strongly related to the interest and engagement of fellow stroke care staff and managers. This is a call for further initiatives to engage entire stroke teams in enhancing the potential for applying registry data in planning, performing and evaluating initiatives to improve stroke care.

Author affiliations

¹Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

²School of Health and Social Science, Dalarna University, Falun, Sweden

³Division of Nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Acknowledgements The authors are grateful to the researchers and clinicians who participated in the validation of the survey tool and to all respondents who completed the survey.

Contributors Validation was performed by SV. TD performed the analyses in dialogue with ACE, LW and MF. ACE, UW, LW and MF attained funding for the study. ACE drafted the paper and completed it in collaboration with all authors, who have approved the final version prior to submission. All authors participated in designing the study, drafting and testing the survey.

Funding The research leading to these results was supported by the Swedish Association of Local Authorities and Regions (SALAR).

Competing interests None declared.

Ethics approval The regional ethical board, Uppsala, Sweden (2013/181).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The complete data set is available at Uppsala University, Sweden.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

REFERENCES

1. Health Resources and Services Administration. *Managing data for performance improvement*. US Department of Health and Human Services. <http://www.hrsa.gov/quality/toolbox/methodology/performanceimprovement/> (accessed 5 Nov 2015).
2. Cadilhac DA, Lannin NA, Anderson CS, *et al*. Protocol and pilot data for establishing the Australian Stroke Clinical Registry. *Int J Stroke* 2010;5:217–26.
3. Centers for Disease Control and Prevention (CDC). Use of a registry to improve acute stroke care—seven states, 2005–2009. *MMWR Morb Mortal Wkly Rep* 2011;60:206–10.
4. Kolas AG, Bulters DO, Cowie CJ, *et al*. Proposal for establishment of the UK Cranial Reconstruction Registry (UKCRR). *Br J Neurosurg* 2014;28:310–14.
5. Jacobsson Ekman G, Lindahl B, Nordin A, eds. *[National quality registries in health care]*. Stockholm, Sweden: Karolinska Institutet University Press, 2014:14–24.
6. Drolet BC, Johnson KB. Categorizing the world of registries. *J Biomed Inform* 2008;41:1009–20.
7. Riksstroke. <http://www.riksstroke.org/eng/> (accessed 5 Nov 2015).
8. Stecksén A, Glader EL, Asplund K, *et al*. Education level and inequalities in stroke reperfusion therapy: observations in the Swedish stroke register. *Stroke* 2014;45:2762–8.
9. Stecksén A, Lundman B, Eriksson M, *et al*. Implementing thrombolytic guidelines in stroke care: perceived facilitators and barriers. *Qual Health Res* 2014;24:412–19.
10. Riksrevisionen. *[The government's investment in national quality registers—are they the way forward? Report 2013:20]*. Stockholm, Sweden: RiR, 2013.
11. Rosén M. *[A review of the national quality registries. The goldmine of healthcare. Proposals for a common investment 2011–2015]*. Stockholm, Sweden: SALAR, 2010.
12. Cadilhac DA, Kim J, Lannin NA, *et al*. National stroke registries for monitoring and improving the quality of hospital care: a systematic review. *Int J Stroke* 2016;11:28–40.
13. Eldh AC, Fredriksson M, Halford C, *et al*. Facilitators and barriers to applying a national quality registry for quality improvement in stroke care. *BMC Health Serv Res* 2014;14:354.
14. Fredriksson M, Eldh AC, Vengberg S, *et al*. Local politico-administrative perspectives on quality improvement based on national registry data in Sweden: a qualitative study using the consolidated framework for implementation research. *Implement Sci* 2014;9:189.
15. Eldh AC, Fredriksson M, Vengberg S, *et al*. Depicting the interplay between organisational tiers in the use of a national quality registry to develop quality of care in Sweden. *BMC Health Serv Res* 2015;15:519.

16. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research*. New York, USA: Sage, 2011.
17. American Educational Research Association, American Psychological Association, National Council on Measurement in Education. *The standards for educational and psychological testing*. Washington, USA: AERA Publications, 2014.
18. Drennan J. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *J Adv Nurs* 2003;42:57–63.
19. Pennert J, Asplund K, Carlberg B, *et al*. Antithrombotic treatment following intracerebral hemorrhage in patients with and without atrial fibrillation. *Stroke* 2015;46:2094–9.
20. Moore GF, Audrey S, Barker M, *et al*. Process evaluation of complex interventions: Medical Research Council guidance. *BMJ* 2015;350: h1258.
21. van der Veer SN, de Keizer NF, Ravelli AC, *et al*. Improving quality of care. A systematic review on how medical registries provide information feedback to healthcare providers. *Int J Med Inform* 2010;79:305–23.
22. Sigsbee B, Bever CTJ, Jones LKJ. Practice improvement requires more than guidelines and quality measures. *Neurology* 2016;86:188–93.
23. Schwamm L, Reeves MJ, Frankel M. Designing a sustainable national registry for stroke quality improvement. *Am J Prev Med* 2006;31:S251–7.
24. Ivers N, Jamtvedt G, Flottorp S, *et al*. Audit and feedback: effects on professional practice and healthcare outcomes. *Cochrane Database Syst Rev* 2012;(6):CD000259.
25. Larsson S, Lawyer P, Garelick G, *et al*. Use of 13 disease registries in 5 countries demonstrates the potential to use outcome data to improve healthcare's value. *Health Aff (Millwood)* 2012;31:220–7.
26. Evans SM, Bohensky M, Cameron PA, *et al*. A survey of Australian clinical registries: can quality of care be measured? *Intern Med J* 2011;41:42–8.
27. Chung SC, Sundström J, Gale CP, *et al*. Comparison of hospital variation in acute myocardial infarction care and outcome between Sweden and United Kingdom: population based cohort study using nationwide clinical registries. *BMJ* 2015;351:h3913.
28. Batalden P, Davidoff F. Teaching quality improvement: the devil is in the details. *JAMA* 2007;298:1059–61.
29. Levay C. Policies to foster quality improvement registries: lessons from the Swedish case. *J Intern Med* 2016;279:160–72.
30. Salinas J, Sprinkhuizen SM, Ackerson T, *et al*. An international standard set of patient-centered outcome measures after stroke. *Stroke* 2016;47:180–6.
31. Aarons GA, Ehrhart MG, Farahnak LR, *et al*. Aligning leadership across systems and organizations to develop a strategic climate for evidence-based practice implementation. *Annu Rev Public Health* 2014;35:255–74.
32. Daudelin DH, Kulick ER, D'Amore K, *et al*. The Massachusetts Emergency Medical Service Stroke Quality Improvement Collaborative, 2009–2012. *Prev Chronic Dis* 2013;10:E161.
33. LaBresh KA, Registry PCNAS. Quality of acute stroke care improvement framework for the Paul Coverdell National Acute Stroke Registry: facilitating policy and system change at the hospital level. *Am J Prev Med* 2006;31:S246–50.
34. Rogers EM. *Diffusion of innovations*. New York, USA: Free Press, 2003.
35. Ovretveit J. Improvement leaders: what do they and should they do? A summary of a review of research. *Qual Saf Healthcare* 2010;19:490–2.