Use of patient reported outcomes in regional cancer centres over time: a retrospective study

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Running Head: factors associated with ESAS uptake over time

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Abstract (250/250)

Introduction: Since 2007 Cancer Care Ontario (CCO) has been collecting the Edmonton Symptom Assessment System (ESAS) as a patient reported outcome measure for use in routine care. The purpose of this project was to evaluate the factors associated with ESAS uptake among cancer patients seen at regional cancer centres between 2007 and 2015 and to examine if these associations have changed over time.

Methods

This is a retrospective cohort study among ESAS-eligible cancer patients in Ontario. We used linked administrative sources of health care data. Our primary outcome for each individual was defined as the rate of ESAS assessments which was analyzed overall and on an annual basis.

Results

We identified 525, 409 unique patients with at least one visit to a cancer centre between 2007 and 2015. The proportion of patients with at least one ESAS increased from 5% in 2007 to 67% in 2015. Analysis demonstrated decreased variation by region and cancer type over time with relative rates (RR) ranging from 0.31 to 13.3 in 2007 versus 0.7 to 1.56 in 2015 for region and 0.03 to 1.0 in 2007 versus 0.55 to 1.0 in 2015 for cancer type. In 2015 women and people living in poorer neighbourhoods had a lower ESAS uptake (RR 0.93 and 0.91 respectively).

Conclusions

Ontario has implemented a patient reported outcome program across the province. Over time, uptake has improved and variation by cancer type and region has decreased. Variation persists with other characteristics which suggest opportunities to improve equity in the program.

Background

Patient reported outcome measures are tools or instruments used to capture a patients' health status from their perspective[1,2]. These measures have been used for some time in research and clinical trials[3]. Increasingly, they are being incorporated into routine clinical care[4,5]. There is evidence that they improve symptom identification, symptom monitoring over time, communication and quality of life[6-9]. There is emerging evidence that their routine use may decrease emergency room visits and even improve survival[10-13].

In 2007, Cancer Care Ontario implemented a province wide program to screen for common cancer symptoms using the Edmonton Symptom Assessment System (ESAS). Other jurisdictions have also ventured into this space. For example, there is a large program of patient reported outcomes in the Netherlands for pediatrics [14]. The Dartmouth Hitchcock Medical Centre has an institution wide program as another [15]. In the United Kingdom the National Health Services routinely collects patient reported outcomes on orthopedic patients and is expanding to other patient populations [16]. Swedish National Quality Registers have also started to collect patient reported outcomes [17]. The program at Cancer Care Ontario however is one of the largest most comprehensive patient reported outcome programs in existence.

The purpose of this project was to evaluate the rate of ESAS use over time among cancer patients seen at regional cancer centres. We also examine the factors associated with ESAS use and if these associations have changed over time. Cancer Care Ontario has made significant effort in supporting the use of ESAS in clinics but the

change has been slow. This paper aims to provide a robust description of the changes in ESAS use over time and by region and to evaluate how other patient, tumor and system factors might be associated with ESAS uptake over time.

Methods

Study design and setting

We conducted a retrospective cohort study among ESAS-eligible cancer patients in Ontario, Canada. The study used administrative sources of health care data linked via a unique encoded identifier. It is not possible to approach this question as a formal implementation evaluation. The implementation of the ESAS program is an ongoing effort at 14 cancer centres that cumulatively reflects a myriad of local efforts. It would not be possible to catalogue these efforts over time or attribute changes in ESAS rates to any one particular endeavour. ESAS implementation went live in all centres in 2007 for lung cancer patients and patients attending palliative care clinics. This was a central strategy direction from CCO. Some centres were able to mobilize and act quickly but others struggled. By 2010 most centres had expanded implementation to include all cancer sites. How this expansion occurred was left to local sites. The ability to document these changes precisely is beyond the scope of this project and efforts to do so are unlikely to be successful given staff changes over the past decade.

In Ontario, radiation treatment and a large proportion of systemic therapy are provided in regional cancer centres. Some systemic therapy is provided at partner hospitals. Some cancer patients (especially those treated only with surgery) are never seen at a cancer center. The provincial Patient Reported Outcomes program that

oversees implementation is active in all regional cancer centres. While it is also active at some partner hospitals, implementation is not consistent and they are not included in this study.

Every five years Cancer Care Ontario publishes a provincial cancer plan which outlines strategic priorities for the organization. Although ESAS was introduced in 2007, in the most recent cancer plan, patient reported outcomes were specifically identified, reflecting the increasing importance of patient reported outcomes within the organization. In order to facilitate patient reported outcome implementation Cancer Care Ontario built and maintains a web-based platform to administer patient reported outcome measures in the clinic. All symptom reports are collected centrally in the Symptom Management Reporting Database. It also provides support to each center for ongoing implementation, sustainability and quality improvement work via service agreements. In spite of the central mandate, each center has implemented in ways that suit local context. Over time cancer centres have been monitored for their performance on how many patients are screened each month.

ESAS is a 9 item instrument that asks patients to rate the intensity of their symptoms on a scale of 0-10[18]. The 9 symptoms included are anxiety, depression, fatigue, drowsiness, pain, shortness of breath, nausea, appetite and wellbeing. It was originally developed in palliative cancer patients but has since been validated in general oncology patients [19]. Implementation started in a limited group of patients, but by 2010 had been rolled out more broadly [20-22]. At the present time, every cancer patient attending a regional cancer centre is encouraged to complete ESAS at a kiosk in

the waiting room before being seen by their medical team. The output is intended to be used in the clinical encounter and to facilitate a discussion about symptoms and care.

Study population and observation window

ESAS-eligible cancer patients are adults (>18 years) who visited any of the regional cancer centers in Ontario between 1st April 2007 and 31st December 2015. Such individuals were identified by the presence of records in the Activity Level Reporting database. Visits to any of the regional cancer center programs were eligible (e.g. radiation program, systemic program) except Preventive Oncology or Research, as ESAS may not occur at those visits types. Exclusion criteria for our cohort were defined as having one or more of the following: invalid unique encoded identifier, missing date of birth, non-first cancer diagnosis, or death date before cohort entry. Individuals with invalid visit program codes in the Activity Level Reporting database were also excluded. Subsequently, if individuals in our cohort had missing information on the covariates of interest, they were excluded as well. Individuals were followed until December 31st 2015, subsequent cancer diagnosis or date of death listed in the Registered Persons Database, whichever occurred first.

Outcome Definition

Our primary outcome for each individual was defined as the rate of ESAS assessments, calculated overall and annually. Patients were assigned to annual cohorts provided they had a clinic visit record in the Activity Level Reporting database during that year. This is aligned with Cancer Care Ontario's measure of symptom screening activity which is also person based. This database contains records of visits and

services occurring at each cancer centre. It is mandatory for each centre to report their volumes of clinical service to Cancer Care Ontario via this database. As such in any specific year, all patients being analyzed were unique from each other. However, over multiple years (that is over multiple annual cohorts), patients are not necessarily unique from year to year. Individuals seen at a cancer centre in multiple years will be counted in each year that they have a visit. Within that year, if they have multiple ESAS's completed, they are only counted once. In any given year, the rate was calculated as the number of ESAS assessments divided by the total follow-up time in that year. This measurement approach adequately allows us to evaluate changes in the screening rate over time. For descriptive purposes, we also examined ESAS uptake as a binary outcome; if individuals had never undertaken an ESAS in that year, they were classified as non-ESAS users, otherwise they were classified as ESAS users. Dates for ESAS were determined from the ESAS database.

Covariate definitions and data sources

Patient, tumor and system variables were chosen to adjust possible confounders when evaluating ESAS rate. Age was retrieved from Registered Persons Database which contains socio-demographic information of all Ontario Health Insurance Plan beneficiaries[23]. The type of cancer diagnosis was determined from the Ontario Cancer Registry [24,25]. Neighborhood income quintile at the start of each year was determined by linking postal codes and residential codes in the Registered Person Database to census data[26]. Region of residence was similarly determined. Cancer Care Ontario's public reporting has long identified variation by region (www.csqi.on.ca). Since it would not be reasonable to place both LHIN and cancer centre into the model and since

region can function as a surrogate for cancer centre, we elected to only incorporate region into the regression model. All CCO reporting is by region. Charlson score [27], was determined based on records from Canadian Institute of Health Information - Discharge Abstracts Database and Same Day Surgery Database. These datasets document diagnoses coded at hospital admissions [28]. The score was calculated with a 2 year look back window. Comorbidity was also assessed using Aggregated Diagnosis Groups based on a 2-year look back period, founded on the John's Hopkins Adjusted Clinical Group Systems [29]. Each patient could be assigned anywhere from 0 to 32 Aggregated Diagnosis Groups. For this study, the number of Aggregated Diagnosis Groups was re-grouped into 3 categories: >=10, between 6 and 10, and between 0 to 5 [30] **.** Each individual's mean resource intensity weight was measured using the Resource Utilization Band based on a two-year look back window. For the purpose of our analyses, the Resource Utilization Band scores were analyzed similar to prior work [31]. Patients were assigned to one of six Resource Utilization Band categories; where 0 implied non-user and 5 was the highest level of resource use. Multiple variables for comorbidity and/or resource use were included in the model to adjust for possible confounding between illness level and the likelihood of having an ESAS (for example, sicker individuals might be more likely to visit the cancer centre and therefore complete and ESAS). This would facilitate a reasonable comparison among regions. An individual was identified as an immigrant if there was a "Date of Landing" record in the Immigration, Refugees and Citizenship Canada Permanent Resident Database) [32]. This dataset is maintained by Citizenship and Immigration Canada. It provides demographic information for all legal immigrants to Canada including country

of birth, citizenship, country of last permanent residence and date of immigration. We further identify immigrants as either recent (<5 years since immigration) or long-term (≥5 years since immigration.

Statistical analyses

We analyzed the overall cohort consisting of all unique individuals accrued over the study period, and we subsequently analyzed each annual cohort of individuals. The distributions of the baseline characteristics of the overall cohort, and distributions of the baseline characteristics for each of the annual cohorts, were assessed. Counts and proportions were used to describe categorical variables; mean, median and interquartile range (IQR) were used to describe the continuous variables. As preliminary work, for each year, histograms were developed to illustrate the distribution of the number of ESAS assessments among those who had at least one ESAS in that year. In addition, the proportion of patients who had at least 1 ESAS assessment in that year was overlaid on the histogram as a horizontal line.

Factors associated with the rate of ESAS uptake was first examined in our overall cohort. As the number of ESAS assessments along with follow-up time varies significantly across patients, a negative binomial regression model was implemented. The natural logarithm of the follow-up time was used as an offset term in the model. A generalized estimating equations (GEE) approach with an exchangeable correlation structure was imposed to account for possible correlation that may arise due to annual repeated measures on each individual (33). Characteristics included into the model were age, sex, income quintile, immigration status, region of residence, cancer type, Charlson group,

Aggregated Diagnosis Group, and Resource Utilization Band group. Both univariable and multivariable regression models were implemented. Collinearity between the variables was assessed using the variance inflation factor, where a cut-off of 5 or higher was used as an indication of collinearity.

Factors associated with the rate of ESAS uptake was also examined on an annual basis, which was done in order to describe if the associations were changing over time. Since there were no repeated observations from the same individual within any given year, we used a negative binomial regression model (without a GEE approach), and conducted both univariable and multivariable analyses. All analyses were completed using SAS version 9.3 and R statistical software version 3.2.3.

Ethics Approval

The study was conducted in accordance with the strict privacy and confidentiality policies of the Institute for Clinical Evaluative Sciences.

Results

We identified 525, 409 unique patients with at least one visit to a cancer centre between 2007 and 2015. 5908 individuals were excluded because of missing covariate information (n=3235) or invalid visit type (n=2673). The group with missing information constitutes about 1% of the cohort across all levels of covariates. This means that some characteristics have far less than 1% missing, and thus cannot be described due to small sample size reporting constraints. Also since there is no reason to suspect a pattern for the missing information and since this small percentage will not influence our final interpretations, we have not provided further descriptions of this group.

Cohort characteristics are presented in Table 1.

The figure in the appendix demonstrates the uptake of ESAS in alternating years from 2007-2015 (for simplicity, not every year is shown). The proportion of patients with at least one ESAS increases from 5% in 2007 to 67% in 2015 (represented by the horizontal dotted line, right sided y-axis). This figure also demonstrates the distribution of the number of ESAS assessments among responders (left sided y-axis). Patients have 1-2 assessments per year most commonly.

The negative binomial GEE model for examining factors associated with the rate of ESAS uptake, using the entire cohort (n=525,409), indicates the relative rates from both univariable and multivariable model were similar except for gender. The estimate from the univariable model showed that females had a 10% higher ESAS uptake rate compared with males. However after multivariable adjustment, the rate of ESAS uptake was 5% lower among females compared with males. With lung as the reference cancer type, all other cancer types were associated with lower ESAS use. With region 7 as the reference level, all other regions were associated with a higher ESAS use (Figure 1).

Table 1A in the appendix describes the characteristics for the annual cohorts in 2007, 2011 and 2015(for simplicity, not every year is shown). The distribution of characteristics is similar from year to year with the exception of immigration status and Charlson score.

The forest plots shown in Figures 2 and 3 illustrate the results from the negative binomial multivariable regression model for years 2007, 2011 and 2015. Figure 2 displays the forest plots for cancer type and comorbidity. In 2007, the relative rates of

ESAS uptake by cancer type were much less than 1 across all cancer types, using lung cancer as a reference, with a relative rate as low as 0.031 for prostate cancer. By 2015 this range had improved considerably, though prostate cancer still had the lowest relative rate.

Figure 3 displays the forest plots for the remaining characteristics. Age had a consistent relative rate across the years. Gender did not have a significant effect in 2007 but was significant in 2011 and 2015. In 2007 there was no significant association between income quintile on ESAS uptake. In 2015, individuals belonging to income quintile 1 and 2 (poorer) were associated with decreased ESAS uptake comparison to income quintile 5 (richer). ESAS uptake in long-term immigrants did not differ significantly from non-immigrants in 2007 but was demonstrated to have lower relative rates in 2011 and 2015. On the other hand, recent immigrants were found to have a 34% decrease in ESAS counts in 2007, but do not differ significantly in 2011 and 2015 compared to non-immigrants. For relative rates of ESAS by region, we observed that largest variation was in 2007, where the range in relative rates was from 0.31 (95% CI 0.26-0.38) to 13.3 (95% CI 11.65-15.20). By 2015, the range had diminished, from 0.7 (95% CI 0.67-0.73) to 1.56 (95% CI 1.51-1.61).

Interpretation

We have demonstrated that ESAS uptake in Ontario cancer centres has increased considerably over time. This a strong demonstration of the ability to implement a patient reported outcome program on a large scale. The amount of variation seen in association with certain variables has improved. For example, there is

much less variation by region and cancer type now, compared to earlier years. Those with comorbid illnesses are more likely to be screened which mitigates concerns that more complicated patients are being missed. However, there is still variation by other variables raising the possibility of ongoing equity issues.

CCO's role as a provincial cancer agency is a key factor in this programmatic uptake. Including patient reported outcomes in the provincial cancer plan makes it a clear strategic priority. Dedicated funding to local centres to support ongoing implementation and execution of the program facilitates this priority. Cancer Care Ontario monitors several performance measures for each regional program including the ESAS screening rate. This is evaluated with senior leadership on a quarterly basis [22, 34]. This performance management system may also have contributed to decreasing variation across regions. Other ongoing quality improvement activities such as annual chart reviews to assess symptom management and patient surveys of their experience with ESAS has likely also contributed to sustaining symptom screening activity.

The implementation has reached all tumor sites, having started primarily in lung. Prostate cancer remains the cancer site screened least often. It has been reported by clinicians that the ESAS items are not always relevant to their patient population[35]. In 2016, Cancer Care Ontario began province wide implementation of the Expanded Prostate Cancer Index-Clinical Practice (EPIC-CP)[36, 37]. This measure has urinary, bowel and sexual function domains which are highly relevant to prostate cancer patients.

The uptake of symptom screening by sex, income and immigration status has changed over time, in some cases improving and in others, worsening. It may be that deprived individuals stand to benefit the most from standardized symptom screening. For example, in Basch *et al*'s study those who were computer inexperienced benefited the most from the intervention [10]. Equity issues will need to be a focus of ongoing quality improvement efforts locally and programmatic changes provincially.

Strengths of this paper are that we included patients attending regional cancer centres in the denominator which ensures that they all were eligible to complete ESAS. The data for this population is extensive and population based. The use of ESAS uptake rate as an outcome accommodates for varying amount of follow up time for each individual patient. The factors evaluated included patient, tumor and system factors.

Limitations

Limitations of the study include that more granular details beyond immigration status (such as fluency in English) were not available. Although we are able to observe how frequently ESAS was completed, we are not able to draw conclusions about how the data was actually used in care. The results may not be generalizable to other jurisdictions. The ALR dataset has not been validated although reporting is mandatory. The CIC dataset has also not been validated.An alternative approach to measuring the outcome might have been a visit based indicator. However, given that all covariates are patient based not visit based, this alternative outcome definition is unlikely to change our conclusions. Futhermore, our measurement approach is more closely aligned with

Cancer Care Ontario's measurement approach, making our observations more directly applicable to the program.

Conclusions

Patient reported outcomes are becoming a more common feature of routine clinical care. The cancer system in Ontario has implemented symptom screening across the system. Cancer specific measures, such as the prostate measure, will hopefully further improve clinician and patient engagement with the program. Opportunities to improve the uptake overall and to decrease variation by equity variables remains.

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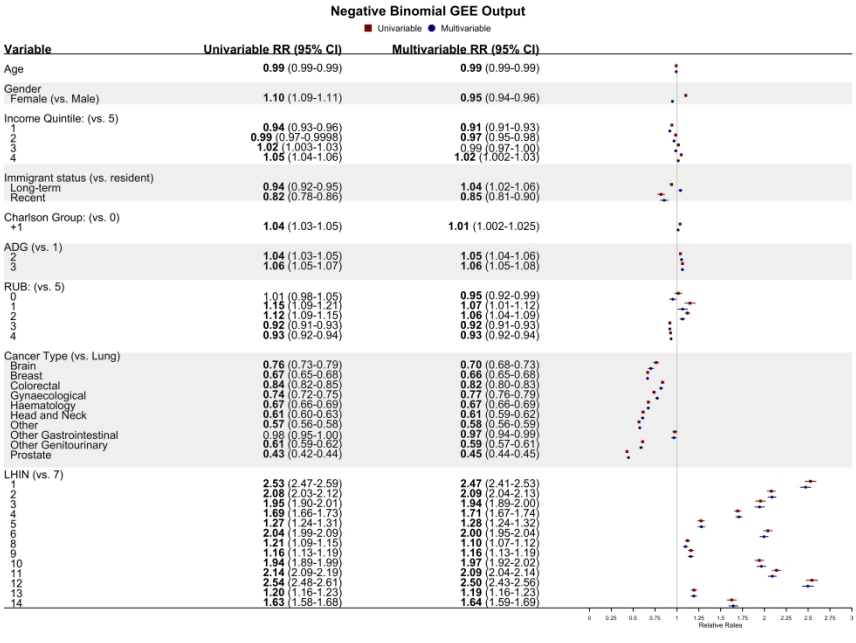


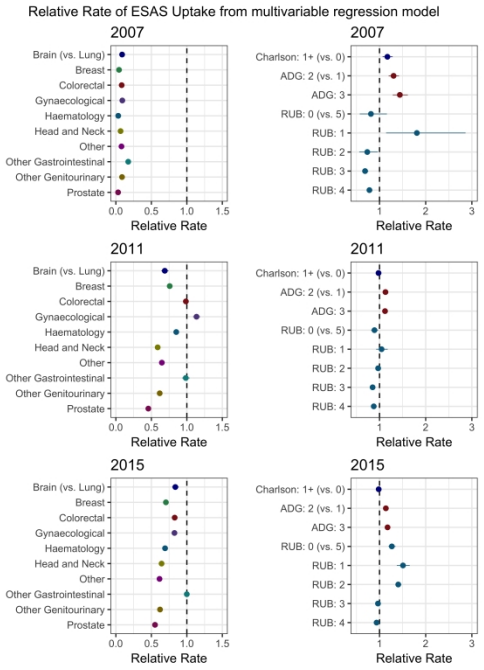
Negative Binomial GEE Output

2540x1693mm (72 x 72 DPI)

Characteristic	RR (95% CI)
Brain (vs. Lung)	0.09 (0.07-0.11)
Breast	0.04 (0.04-0.05)
Colorectal	0.08 (0.07-0.09)
Gynaecological	0.09 (0.08-0.10)
Haematology	0.03 (0.03-0.04)
Head and Neck	0.07 (0.06-0.08)
Other	0.08 (0.07-0.09)
Other Gastrointestinal	0.17 (0.14-0.21)
Other Genitourinary	0.09 (0.07-0.10)
Prostate	0.03 (0.03-0.04)

Characteristic	RR (95% CI)
Brain (vs. Lung)	0.69 (0.64-0.74)
Breast	0.76 (0.73-0.79)
Colorectal	0.99 (0.95-1.03)
Gynaecological	1.14 (1.09-1.19)
Haematology	0.85 (0.82-0.88)
Head and Neck	0.59 (0.56-0.62)
Other	0.65 (0.62-0.67)
Other Gastrointestinal	0.98 (0.93-1.04)
Other Genitourinary	0.62 (0.59-0.65)
Prostate	0.46 (0.44-0.47)

Characteristic	RR (95% CI)
Brain (vs. Lung)	0.84 (0.79-0.88)
Breast	0.70 (0.69-0.72)
Colorectal	0.83 (0.80-0.85)
Gynaecological	0.83 (0.80-0.85)
Haematology	0.69 (0.67-0.71)
Head and Neck	0.64 (0.62-0.67)
Other	0.61 (0.60-0.63)
Other Gastrointestinal	1.00 (0.96-1.04)
Other Genitourinary	0.62 (0.60-0.65)
Prostate	0.55 (0.54-0.57)



Characteristic	RR (95% CI)
Charlson: 1+ (vs. 0)	1.17 (1.07-1.28)
ADG: 2 (vs. 1)	1.30 (1.20-1.42)
ADG: 3	1.44 (1.29-1.61)
RUB: 0 (vs. 5)	0.81 (0.57-1.16)
RUB: 1	1.81 (1.14-2.86)
RUB: 2	0.73 (0.56-0.96)
RUB: 3	0.69 (0.62-0.76)
RUB: 4	0.78 (0.72-0.85)

Characteristic	RR (95% CI)
Charlson: 1+ (vs. 0)	0.98 (0.95-1.00)
ADG: 2 (vs. 1)	1.13 (1.10-1.15)
ADG: 3	1.12 (1.09-1.15)
RUB: 0 (vs. 5)	0.89 (0.82-0.97)
RUB: 1	1.04 (0.93-1.18)
RUB: 2	0.97 (0.91-1.03)
RUB: 3	0.85 (0.83-0.87)
RUB: 4	0.88 (0.86-0.89)

Characteristic	RR (95% CI)
Charlson: 1+ (vs. 0)	0.98 (0.96-1.00)
ADG: 2 (vs. 1)	1.14 (1.12-1.16)
ADG: 3	1.17 (1.15-1.20)
RUB: 0 (vs. 5)	1.27 (1.19-1.35)
RUB: 1	1.51 (1.38-1.65)
RUB: 2	1.41 (1.34-1.47)
RUB: 3	0.97 (0.95-0.99)
RUB: 4	0.94 (0.92-0.95)

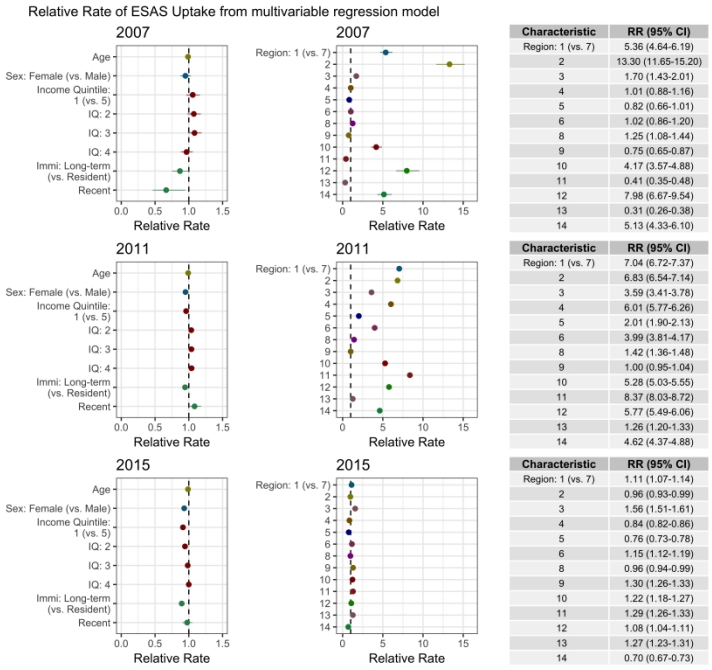
Relative rate of ESAS uptake from multi variable regression model

2540x1693mm (72 x 72 DPI)

Characteristic	RR (95% CI)
Age	0.99 (0.99-0.99)
Sex: Female (vs. Male)	0.95 (0.88-1.03)
Income Quintile: 1 (vs. 5)	1.06 (0.96-1.16)
IQ: 2	1.07 (0.98-1.18)
IQ: 3	1.08 (0.99-1.19)
IQ: 4	0.97 (0.88-1.06)
Immi: Long-term (vs. Resident)	0.87 (0.75-1.00)
Recent	0.66 (0.47-0.95)

Characteristic	RR (95% CI)
Age	0.99 (0.99-0.99)
Sex: Female (vs. Male)	0.95 (0.93-0.97)
Income Quintile: 1 (vs. 5)	0.96 (0.94-0.99)
IQ: 2	1.04 (1.01-1.06)
IQ: 3	1.04 (1.01-1.06)
IQ: 4	1.04 (1.02-1.07)
Immi: Long-term (vs. Resident)	0.94 (0.91-0.99)
Recent	1.08 (1.00-1.18)

Characteristic	RR (95% CI)
Age	0.99 (0.99-0.99)
Sex: Female (vs. Male)	0.93 (0.92-0.95)
Income Quintile: 1 (vs. 5)	0.91 (0.90-0.93)
IQ: 2	0.94 (0.93-0.96)
IQ: 3	0.98 (0.97-1.00)
IQ: 4	1.00 (0.98-1.02)
Immi: Long-term (vs. Resident)	0.90 (0.88-0.91)
Recent	0.97 (0.90-1.05)



Characteristic	RR (95% CI)
Region: 1 (vs. 7)	5.36 (4.64-6.19)
2	13.30 (11.65-15.20)
3	1.70 (1.43-2.01)
4	1.01 (0.88-1.16)
5	0.82 (0.66-1.01)
6	1.02 (0.86-1.20)
8	1.25 (1.08-1.44)
9	0.75 (0.65-0.87)
10	4.17 (3.57-4.88)
11	0.41 (0.35-0.48)
12	7.98 (6.67-9.54)
13	0.31 (0.26-0.38)
14	5.13 (4.33-6.10)

Characteristic	RR (95% CI)
Region: 1 (vs. 7)	7.04 (6.72-7.37)
2	6.83 (6.54-7.14)
3	3.59 (3.41-3.78)
4	6.01 (5.77-6.26)
5	2.01 (1.90-2.13)
6	3.99 (3.81-4.17)
8	1.42 (1.36-1.48)
9	1.00 (0.95-1.04)
10	5.28 (5.03-5.55)
11	8.37 (8.03-8.72)
12	5.77 (5.49-6.06)
13	1.26 (1.20-1.33)
14	4.62 (4.37-4.88)

Characteristic	RR (95% CI)
Region: 1 (vs. 7)	1.11 (1.07-1.14)
2	0.96 (0.93-0.99)
3	1.56 (1.51-1.61)
4	0.84 (0.82-0.86)
5	0.76 (0.73-0.78)
6	1.15 (1.12-1.19)
8	0.96 (0.94-0.99)
9	1.30 (1.26-1.33)
10	1.22 (1.18-1.27)
11	1.29 (1.26-1.33)
12	1.08 (1.04-1.11)
13	1.27 (1.23-1.31)
14	0.70 (0.67-0.73)

Relative rate of ESAS uptake from multi variable regression model

2540x1693mm (72 x 72 DPI)

Table 1: Cohort characteristics at baseline

Characteristic	Level	N	Proportion
Overall		525409	1.00
Age (mean) (median, IQR)		64.37 65 (56 – 75)	
Sex	Female	274476	0.52
	Male	250993	0.48
Income Quintile	1	93866	0.18
	2	103577	0.20
	3	103228	0.20
	4	109642	0.21
	5 (Wealthiest)	115096	0.22
Immigrant Status	Long-term	37114	0.07
	Recent	6104	0.01
	Resident	482191	0.92
Type of Cancer	Brain	8119	0.02
	Breast	111543	0.21
	Colorectal	54871	0.10
	Gynaecological	35022	0.07
	Haematology	52609	0.10
	Head and Neck	20277	0.04
	Lung	50541	0.10
	Other	67268	0.13
	Other Gastrointestinal	21048	0.04
	Other Genitourinary	24552	0.05
	Prostate	79559	0.15
Region	1	30053	0.06
	2	40377	0.08
	3	24625	0.05
	4	64800	0.12
	5	21872	0.04
	6	36791	0.07
	7	44241	0.08
	8	59952	0.11
	9	60268	0.11
	10	25102	0.05
	11	53126	0.10
	12	21124	0.04
	13	30542	0.06
	14	12536	0.02

Charlson Score	0	462189	0.88
	1+	63220	0.12
ADG Score	1 – 5	188057	0.36
	6 – 10	235163	0.45
	10+	102189	0.19
RUB Score	0	14701	0.03
	1	6380	0.01
	2	27597	0.05
	3	219284	0.42
	4	135096	0.26
	5	122351	0.23

ADG: Aggregated diagnosis groups
RUB: Resource utilization band

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

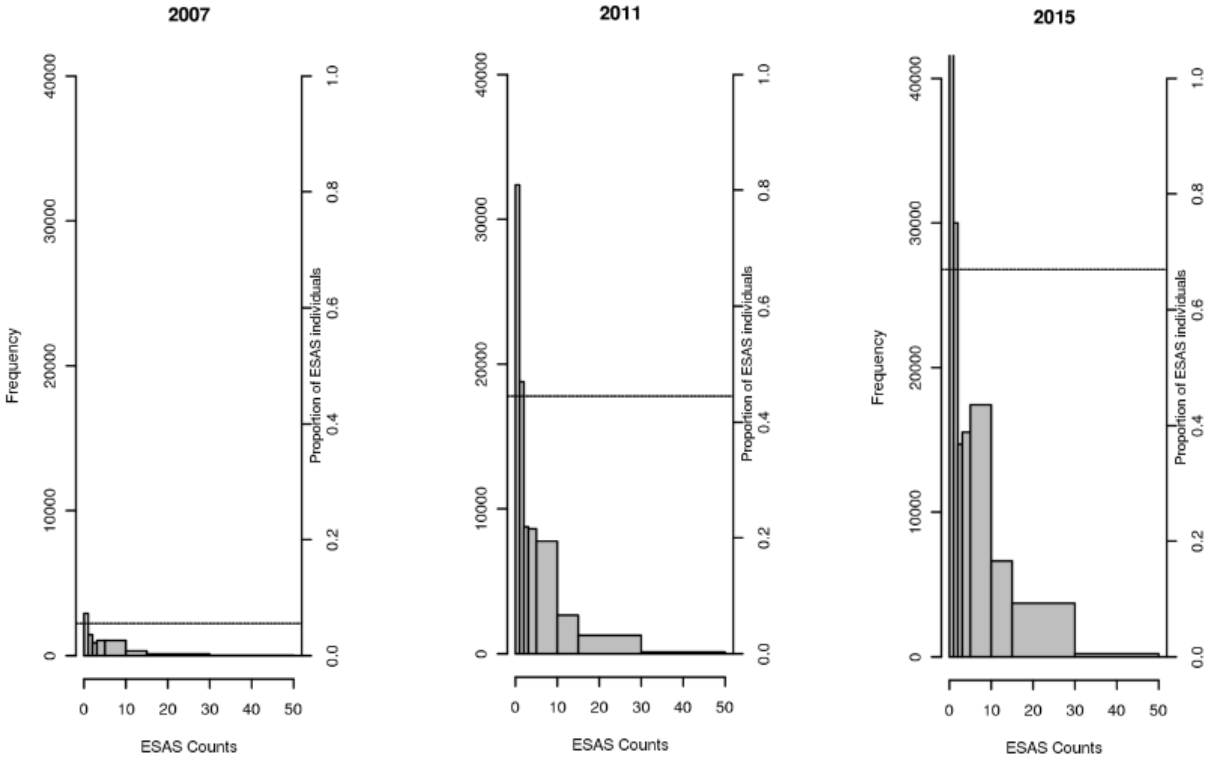
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Figure 1A. Distribution of ESAS counts among ESAS users

The bars represent the number of patients with a particular number of ESAS assessment in a given year, using the y-axis to the left. The horizontal line represents the proportion of individuals who have at least 1 ESAS in that year, using the y-axis to the right.



Appendix:

Table 1A: Cohort characteristics by year.

Year		**2007**		**2011**		**2015**	
Characteristic	Level	N	Proportion	N	Proportion	N	Proportion
Overall		139977		180869		213705	
Age (mean) Median (IQR)		64.02 65 (55 – 74)		64.52 66 (56 – 75)		65.20 66 (57 – 75)	
Sex	Female	73916	0.53	94681	0.52	113895	0.53
	Male	66061	0.47	86188	0.48	99810	0.47
Income Quintile	1	24177	0.17	30006	0.17	35827	0.17
	2	27164	0.19	34579	0.19	40644	0.19
	3	27242	0.19	35321	0.20	42154	0.20
	4	28882	0.21	38671	0.21	46077	0.22
	5 (Wealthiest)	32512	0.23	42292	0.23	49003	0.23
Immigrant Status	Long-term	7247	0.05	12422	0.07	20353	0.10
	Recent	1195	0.01	1622	0.01	1273	0.01
	Resident	131535	0.94	166825	0.92	192079	0.90
Type of Cancer	Brain	1978	0.01	2528	0.01	2848	0.01
	Breast	35907	0.26	44569	0.25	51062	0.24
	Colorectal	12562	0.09	16599	0.09	19927	0.09
	Gynaecological	9313	0.07	11656	0.06	13292	0.06
	Haematology	15501	0.11	20192	0.11	26534	0.12
	Head and Neck	6253	0.04	7409	0.04	8438	0.04
	Lung	8060	0.06	10927	0.06	13813	0.06
	Other	14581	0.10	20442	0.11	27418	0.13
	Other Gastrointestinal	3013	0.02	4521	0.02	6012	0.03

	Other Genitourinary	5354	0.04	7275	0.04	8914	0.04
	Prostate	27455	0.20	34751	0.19	35447	0.17
Region	1	8654	0.06	10025	0.06	9880	0.05
	2	11433	0.08	12965	0.07	14020	0.07
	3	6105	0.04	7663	0.04	9458	0.04
	4	19208	0.14	23199	0.13	24567	0.11
	5	4368	0.03	6187	0.03	10791	0.05
	6	8483	0.06	12224	0.07	15993	0.07
	7	12453	0.09	15456	0.09	19600	0.09
	8	14674	0.10	21037	0.12	26886	0.13
	9	15182	0.11	21437	0.12	25975	0.12
	10	6577	0.05	8260	0.05	9417	0.04
	11	15752	0.11	18963	0.10	20239	0.09
	12	3563	0.03	7584	0.04	9371	0.04
	13	9064	0.06	10706	0.06	12211	0.06
	14	4461	0.03	5163	0.03	5297	0.02
Charlson Score	0	123545	0.88	156043	0.86	181670	0.85
	1+	16432	0.12	24826	0.14	32035	0.15
ADG	1 – 5	38581	0.28	52790	0.29	63984	0.30
	6 – 10	67965	0.49	86089	0.48	98061	0.46
	10+	33431	0.24	41990	0.23	51660	0.24
RUB Score	0	1011	0.01	1713	0.01	2085	0.01
	1	447	0.00	757	0.00	807	0.00
	2	1940	0.01	3293	0.02	4003	0.02
	3	45437	0.32	60663	0.34	69393	0.32
	4	45042	0.32	56119	0.31	64884	0.30
	5	46100	0.33	58324	0.32	72533	0.34

ADG: Aggregated diagnosis groups

RUB: Resource utilization band