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RESEARCH ARTICLE (ORIGINAL)

Prevalence, incidence, and sociodemographic and clinical characterization of individuals with an intestinal or urinary stoma in Portugal

Prevalência, incidência e caracterização sociodemográfica e clínica das pessoas com estoma de eliminação em Portugal

Prevalencia, incidencia y caracterización sociodemográfica y clínica de las personas con ostomía de eliminación en Portugal

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Abstract
Background: Data characterizing individuals with a stoma in Portugal is limited. Establishing epidemiological estimates can enhance understanding of this population and facilitate the adaptation of healthcare models.
Objectives: To estimate the prevalence and incidence of individuals in Portugal who have undergone intestinal or urinary ostomy in 2021.
Methodology: Observational, longitudinal, and retrospective study using a stoma appliance dispensing database.
Results: In 2021, an estimated 22,045 individuals had at least one stoma, with 19,793 [95%CI:19,599;19,994] having an intestinal/urinary stoma. Most of these individuals were men (61.4%) with a mean age of 70.5 years and resided in the inland region of Portugal. Colostomy was the most prevalent type of intestinal/urinary stoma (48.8%). The estimated incidence of new cases was 6,622, of which 5,834 [95%CI:5,680;5,984] were intestinal/urinary stomas.
Conclusion: These results characterize the profile of individuals with intestinal and urinary stomas in Portugal. They may be useful in adjusting prevention and health monitoring programs for this population and allocating specialized resources.

Keywords: incidence; epidemiological monitoring; ostomy; prevalence.

Resumo
Enquadramento: Dados que caracterizam as pessoas com estoma em Portugal são escassos. Estabelecer estimativas epidemiológicas pode melhorar o conhecimento sobre esta população e adaptar modelos de cuidados de saúde.
Objetivos: Estimar a prevalência e incidência de pessoas com estoma de eliminação em Portugal em 2021.
Metodologia: Estudo observacional, longitudinal e retrospetivo, a partir de uma base de dados de dispensa de dispositivos para ostomia.
Resultados: Em 2021, o número estimado de pessoas com pelo menos um estoma foi de 22.045. Entre estes, 19.793 [IC95%:19.599;19.994] tinham um estoma de eliminação. Na sua maioria eram homens (61,4%), em média tinham 70,5 anos e residiam preferencialmente na região interior do país. O tipo de estoma de eliminação mais prevalente foi a colostomia (48,8%). A incidência estimada de novos casos foi de 6.622, sendo 5.834 [IC95%:5.680;5.984] referentes a estomas de eliminação.
Conclusão: Estes resultados permitiram caracterizar o perfil das pessoas com estoma de eliminação em Portugal. Poderão ser úteis para ajustar os programas de prevenção/acompanhamento em saúde desta população e ainda alocar recursos especializados.

Palavras-Chave: incidência; monitorização epidemiológica; ostomia; prevalência

Resumen
Marco contextual: Los datos que caracterizan a las personas con estomas en Portugal son escasos. Establecer estimaciones epidemiológicas puede mejorar el conocimiento sobre esta población y adaptar modelos sanitarios.
Objetivos: Estimar la prevalencia y la incidencia de personas con estoma de eliminación en Portugal en 2021.
Metodología: Estudio observacional, longitudinal y retrospectivo, basado en una base de datos de dispensaciones de dispositivos de ostomía.
Resultados: En 2021, el número estimado de personas con al menos un estoma era de 22.045, de las cuales 19.793 [IC95%:19.599;19.994] tenían un estoma de eliminación. La mayoría de ellos eran hombres (61,4%), tenían una edad media de 70,5 años y vivían principalmente en el interior del país. El tipo de estoma de eliminación más frecuente era la colostomía (48,8%). La incidencia estimada de nuevos casos fue de 6.622, de los cuales 5.834 [IC95%:5.680;5.984] eran estomas de eliminación.
Conclusión: Estos resultados han permitido caracterizar el perfil de las personas con estoma de eliminación en Portugal. Podrían ser útiles para ajustar los programas de prevención/seguimiento de la salud de esta población y para asignar recursos especializados.

Palabras clave: incidencia; seguimiento epidemiológico; ostomía; prevalencia

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Introduction

In recent years, there has been a global increase in the number of individuals with one or more stomas. Colorectal cancer is the most common diagnosis associated with the creation of an intestinal stoma (Silva et al., 2020). It is expected that the number of people with an intestinal stoma will continue to rise due to the growing incidence of this type of cancer. It is the third most common type of cancer worldwide, with around 1.9 million new cases per year. Its incidence is expected to rise by 60% by 2040 (International Agency for Research on Cancer, 2020). The same is true of urinary stomas. Bladder cancer is the seventh most prevalent type of cancer worldwide, with around 570,000 new cases per year (International Agency for Research on Cancer, 2020).

The rise in the population with one or more stomas and the consequent need for specialized healthcare require public policies that guarantee accessibility to devices, healthcare professionals, and services that aid in the management of their condition (Diniz et al., 2021). To achieve this goal, obtaining reliable epidemiological data on individuals with one or more stomas in Portugal is crucial. This information can enhance our understanding of this population and aid in the development of tailored health policies and action plans that meet their unique characteristics and needs. Therefore, the objective of this study was to determine the prevalence and incidence of individuals with one or more intestinal/urinary stomas in the Portuguese population in 2021.

Background

Ostomy comes from two Greek words, *os* and *tomé*, meaning the opening of a mouth, and indicates the exteriorization of a hollow organ at a point other than its natural opening to create a stoma (Neto et al., 2016).

Stomas can be classified as temporary or permanent based on duration, or according to their function, such as breathing stoma, nutritional stoma, or drainage stoma (Neto et al., 2016).

Drainage (intestinal and urinary) stomas are surgical openings in the abdominal wall that promote the elimination of waste, such as feces and urine. Intestinal stomas are created when a portion of the intestine suffers from dysfunction, obstruction, or injury (Neto et al., 2016). The intestinal ostomy can be referred to as an ileostomy (ileum) or a colostomy (colon), depending on the segment of the intestine that is excised (Babakhanlou et al., 2022). Urinary ostomies are indicated in diseases of the renal pelvis, ureters, bladder, and urethra to preserve renal function. The stoma can be designated based on the organ or segment it is derived from the skin. These include nephrostomy for the kidney, ureterostomy for the ureter, cystostomy for the bladder, urethrostomy for the urethra, and urostomy for cases where the bladder is removed and a new reservoir is created using an ileum or colon conduit to the ureters, which is then brought to the skin (Babakhanlou et al., 2022; National Institute of Diabetes and Digestive and Kidney Diseases, 2020; Schultz et al., 2015).

Several epidemiological studies have been conducted over the years to understand the characteristics of this population. In Europe, there are approximately 700,000 individuals with an intestinal or urinary stoma (European Ostomy Association, 2012). In Portugal, the available information is limited (Romão et al., 2020), with estimates ranging from 16,000 (Hospital Fernando Fonseca, 2020) to 25,000 (Cabral, 2009) people with a stoma. There is a lack of current and robust data on the incidence and prevalence of people with one or more stomas in the Portuguese population. Estimating the incidence, prevalence, and sociodemographic characteristics of the population with a stoma in Portugal can aid in understanding the challenges associated with this condition. This evidence can improve healthcare for this population and inform better healthcare decisions that meet the needs and expectations of people living with a stoma.

Research question

What is the incidence and prevalence of individuals with one or more intestinal or urinary stomas in Portugal in 2021?

Methodology

A multicenter, retrospective, longitudinal observational study was conducted using secondary data extracted from an anonymized population database called BD Phollow. This database contains information on the dispensing of medication and medical devices covered by the National Health Service (SNS) reimbursement program in community pharmacies affiliated to the National Pharmacies Association (ANF) and using the Sifarma® computerized dispensing system (n = 2,411, approximately 83% of all community pharmacies in Portugal), which was locally anonymized and then shared with the Center for Health Studies and Evaluation (CEFAR). The study analyzed all records of stoma appliance dispensing in mainland Portugal and the Autonomous Region of Madeira from 2020 to 2021, as included in the reimbursement scheme outlined in Ordinance no. 284/2016, published on INFARMED's website. The Autonomous Region of the Azores was excluded from the study due to the recent implementation of device reimbursement through community pharmacies.

Each record in the sample includes the patients's unique identifier (ID), gender, age, the code of the dispensing pharmacy, the code of the dispensed product, and the date of dispensation. The pharmacy code is solely used for region allocation, with data from pharmacies in the same regions of interest (e.g. districts) being aggregated for analysis. The products were categorized based on the type of stoma described in INFARMED's list of products, which includes gastrostomy, tracheostomy, and intestinal and urinary ostomy. For the intestinal

and urinary stoma appliances, a second categorization was made based on the group and designation of the medical device, specifically urinary ostomy, colostomy, and ileostomy. Thus, patients were grouped into five categories based on the identification of the purchased products. It is important to note that the patient may have purchased other products without specifying their purpose. 1) Urinary stoma - those who only purchased urostomy (except continent urostomy), nephrostomy, or ureterostomy products; 2) Colostomy - those who only purchased colostomy products; 3) Ileostomy - those who only purchased ileostomy products; 4) Multiple stoma - those who purchased urinary ostomy and colostomy or ileostomy products; 5) Multiple users - those who purchased ileostomy and colostomy products. For this study, we allocated patients with intestinal or urinary stoma products who had also purchased tracheostomy and gastrostomy products to the intestinal and urinary stoma cohort. To estimate the total number of people with a stoma in mainland Portugal and the Autonomous Region of Madeira, a linear extrapolation was performed based on the sample taken from 2,411 pharmacies. This was done by calculating the average number of packages purchased per person from the total number of packages purchased. Based on the total number of reimbursed packages reported by INFARMED (2021) and assuming the same stratification and population distribution as the sample collected, an estimate was made for the total number of people with a stoma in Portugal.

The study defined the estimated incidence and prevalence of intestinal and urinary stomas in 2021 as follows: i) incidence (per 100,000 person-years) - the number of people with at least one intestinal or urinary stoma appliance dispensed in 2021 and had no dispensing records in 2020, divided by the population living in mainland Portugal and the Autonomous Region of Madeira in 2021 according to INE data for that year; ii) prevalence (per 1,000 person-years) - number of people identified with at least one intestinal or urinary stoma appliance dispensed in 2021, divided by the population living in mainland Portugal and the Autonomous Region of Madeira in 2021 according to data from INE for that year (Instituto Nacional de Estatística, 2021; Noordzij et al., 2010). The total number of people with a stoma was estimated by calculating confidence intervals based on the average number of packages purchased per person in the corresponding sample, in each stratification (using a sampling factor equivalent to the quotient between the packages reported by INFARMED and the number of packages in the sample). The proportion of incidents was used to calculate confidence intervals, with a 95%CI.

The cohort's demographic data for patients with intestinal or urinary stomas was segmented into five categories. Gender and age groups were summarized using absolute frequencies, while age was summarized using measures of central tendency, such as mean, median, standard deviation, and quartiles 1 and 3. The analysis of incidence and prevalence was conducted for the entire population, as well as for the three main categories of individuals with intestinal and urinary stomas (colostomy, ileostomy, and urinary stoma). The data was stratified by region, taking into account the 18 districts of mainland Portugal and the Autonomous Region of Madeira, as well as age and gender. To make analyzing the distribution by district easier, we used color codes to represent the distribution by quartiles in each analysis.

The study received a favorable opinion from the Ethics Committee of the Northern Health School of the Portuguese Red Cross (No. 9 / 2023). We only used secondary data in this study, so we did not obtain informed consent from patients. All data was processed in aggregate form, preventing the identification of any individuals.

Results

Prevalence

In 2021, it was estimated that there would be 22,045 (95%CI: 21,820-22,281) individuals in mainland Portugal and the Autonomous Region of Madeira with at least one stoma. Of these individuals, 89.8% had at least one intestinal or urinary stoma, which corresponds to a total of 19,793 (95%CI: 19,599-19,994) people. The study found that colostomy was the most common type of stoma, accounting for 48.8% of cases, followed by ileostomy at 22.6% and urinary stoma at 21.1%. This corresponded to a total of 9,660 cases (95%CI: 9,538-9,788) for colostomy, 4,483 cases (95%CI: 4,390-4,583) for ileostomy, and 4,174 cases (95%CI: 4,083-4,272) for urinary stoma. In addition, the study estimated that 533 individuals (2.7%; 95%CI: 505-567) had one intestinal stoma and one urinary stoma, while 944 individuals (4.8%; 95%CI: 907-986) had only one intestinal stoma but switched between colostomy and ileostomy appliances, making it difficult to characterize them. These findings are presented in Table 1.

Table 1

Estimated number of people with an intestinal or urinary stoma, percentage, and global prevalence per 100,000 inhabitants, by type of stoma, gender, and age

	Total intestinal and urinary stomas	Colostomy	Ileostomy	Urinary stoma	Multiple stomas	Multiple users
Global						
N* **(95%CI)**	19,793 (19,599-19,994)	9,660 (9,538-9,788)	4,483 (4,390-4,583)	4,174 (4,083-4,272)	533 (505-567)	944 (907-986)
%	100	48.8	22.6	21.1	2.7	4.8
Prevalence*	195.7	95.8	44.3	41.3	5.3	9.3
Gender						
Male	61.4%	57.2%	61.3%	70.8%	64.0%	60.6%
Female	38.6%	42.8%	38.7%	29.2%	36.0%	39.4%
Prevalence**						
Male	252.6	114.2	57.2	62.1	7.1	12.0
Female	144.1	77.5	32.7	23.1	3.6	7.1
Age						
Mean (*sd*)	70.5 (14.2)	72.7 (13.5)	67.1 (15.8)	66.6 (15.0)	64.8 (14.3)	67.6 (15.3)
Median (IQR)	72 (63;81)	74 (65;83)	69 (59;78)	68 (59;77)	67 (57;75)	70 (60;78)
Age groups						
< 50	7.6%	5.7%	12%	6.7%	13.6%	10.6%
50-59	11.6%	11.0%	13.5%	10.9%	16%	13.2%
60-69	21.9%	19.2%	25.2%	23.4%	28%	25.7%
70-79	29.6%	28.6%	27.7%	33.7%	28.9%	28.5%
> = 80	29.3%	35.5%	21.6%	25.3%	13.6%	22%
Prevalence**						
<50	27.3	9.7	9.5	4.9	1.3	1.8
50-59	156.6	71.2	40.3	30.7	5.8	8.5
60-69	324.1	137.4	84.2	73.3	11.2	18.1
70-79	553.6	261.8	118.0	133.9	14.5	25.5
> =8 0	816.3	488.9	139.4	148.5	10.2	29.2

Note. IQR = Interquartile range; *SD* = Standard deviation; 95%CI = Confidence intervals set at 95% for proportions; N* = Estimated population; **Estimated prevalence for 100,000 people.

The mean age of individuals with at least one intestinal or urinary stoma was 70.5 years (*SD* = 14.2), and the majority were men (61.4%). This corresponds to an estimated prevalence of 252.6 cases per 100,000 men in Portugal. The prevalence of individuals with an intestinal or urinary stoma increases with age, with the biggest difference between the 50-59 and 60-69 age groups. These results are also presented in Table 1.

Men had a higher prevalence of intestinal or urinary stomas, varying by the type of ostomy. For colostomies, 57.2% were men, corresponding to an estimated prevalence of 114.2 cases per 100,000 men. For ileostomies, 61.3% were men, with a prevalence of 57.2 cases per 100,000 men. For urinary stomas, 70.8% were men, with a prevalence of 62.1 cases per 100,000 men. Regarding multiple stomas, 64% of cases were men, which equates to 7.1 cases per 100,000 men.

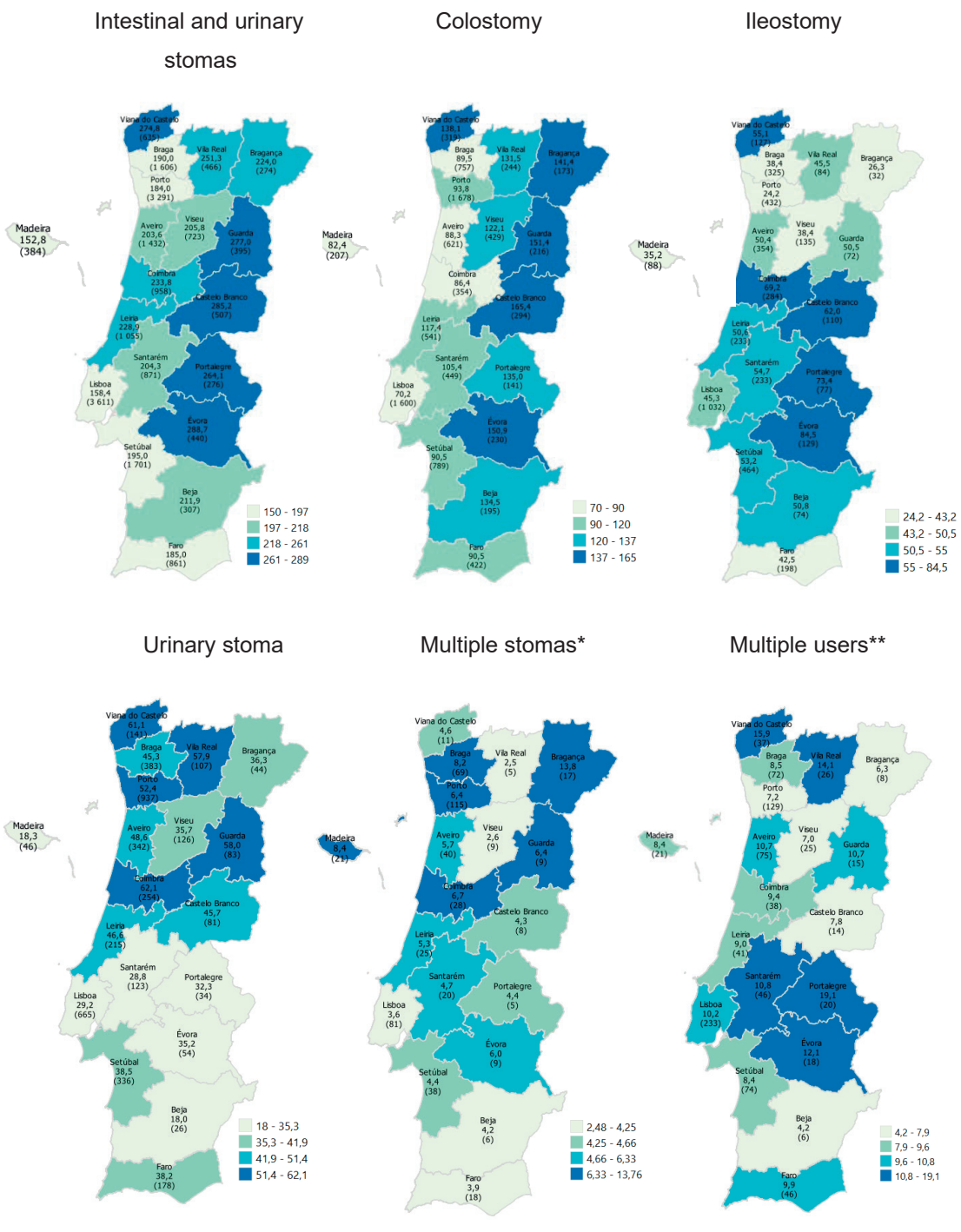
The highest proportion of people with a colostomy are in their 80s or older, with the rest being between 70 and 79 years old. Table 1 shows the mean age of people based on the type of intestinal or urinary stoma.

The districts of Évora, Castelo Branco, Guarda, Viana do Castelo, and Portalegre have the highest estimated prevalence of people with at least one intestinal or uri-

nary stoma, with prevalences of more than 264 cases per 100,000 inhabitants.
Castelo Branco, Guarda, Évora, Bragança, and Viana do Castelo have the highest prevalence of colostomies, with between 165.4 and 138.1 cases per 100,000 inhabitants. Évora, Portalegre, Coimbra, Castelo Branco, and Viana do Castelo had the highest prevalence of ileostomies, with between 55.1 and 84.5 cases per 100,000 inhabitants. Coimbra, Viana do Castelo, Guarda, Vila Real, and Porto had the highest prevalence of urinary stomas, with between 52.4 and 62.1 cases per 100,000 inhabitants. These results are shown in Figure 1.

Figure 1

Estimated number of people with an intestinal or urinary stoma in Portugal and prevalence per 100,000 inhabitants, by region and type of stoma in 2021



Note. * People with a colostomy + urinary stoma or ileostomy + urinary ostomy ** People who purchase colostomy and ileostomy appliances.

The majority of people with an intestinal or urinary stoma use a two-piece system, especially those with an ileostomy, as shown in Table 2. Additionally, most individuals use a flat base plate.

Table 2

Estimated number of people with an intestinal or urinary stoma in 2021, by type of stoma bag used

Type of stoma bag	Colostomy *N** (%)	Ileostomy *N** (%)	Urinary ostomy *N** (%)
One-piece	3,623 (37.5)	1,008 (22.5)	1,185 (28.4)
Flat	3,518 (97.1)	845 (83.8)	1,117 (94.3)
Convex	43 (1.2)	120 (11.9)	43 (3.6)
Flat and convex	51 (1.4)	43 (4.3)	25 (2.1)
N/A *	11 (0.3)	0 (0.0)	0 (0.0)
Two-piece	5,699 (59.0)	3,281 (73.2)	2,776 (66.5)
Flat	4,445 (78.0)	2,008 (61.2)	2,146 (77.3)
Convex	924 (16.2)	941 (28.7)	458 (16.5)
Flat and convex	245 (4.3)	302 (9.2)	153 (5.5)
N/A *	85 (1.5)	30 (0.9)	19 (0.7)
One- and two-pice	338 (3.5)	197 (4.4)	213 (5.1)
Flat	256 (75.9)	105 (53.5)	157 (73.6)
Convex	8 (2.3)	14 (7.1)	3 (1.4)
Flat and convex	74 (21.8)	78 (39.4)	53 (25.0)

Note. *N** = Estimated population; N/A * = No data regarding the type of base plate.

Incidence

In 2021, the incidence of one or more stomas in Portugal (mainland and Autonomous Region of Madeira) was 6,622 (95%CI: 6,469-6,784). Of these, 5,834 reported a new intestinal or urinary stoma (95%CI: 5,680-5,984), which corresponded to 88.0% of new cases.

Among people with a new intestinal or urinary stoma in 2021, it is estimated that 1,930 had a colostomy (33.1%; 95%CI: 1,830-2,030), 1,719 had an ileostomy (29.5%; 95%CI: 1,625-1,814), and 1,590 had a urinary stoma (27.2%; 95%CI: 1,499-1,683). Out of the 6,681 participants, 151 (2.6%; 95%CI: 122-181) had multiple stomas, including a urinary stoma and a colostomy or an ileostomy. Additionally, 442 participants had only an intestinal stoma but used both colostomy and ileostomy appliances (multiple users), making it difficult to characterize them accurately (7.6%; 95%CI: 393-492).

In terms of the estimated incidence of individuals with at least one new intestinal or urinary stoma, 61.4% were men, corresponding to an incidence of 74.4 cases per 100,000 men in Portugal. Table 3 shows that the average age of individuals with a new stoma was 68.1 years.

The estimated incidence of individuals with a new stoma was higher in those aged 70 or over.

Table 3

Estimated number of individuals with a new intestinal or urinary stoma and estimated incidence per 100,000 habitantes, by gender and age

	Total intestinal and urinary ostomies	Colostomy	Ileostomy	Urinary ostomy	Multiple ostomies	Multiple users
Global						
N* **(IC95)**	5,834 (5,680-5,984)	1,930 (1,830-2,030)	1,719 (1,625-1,814)	1,590 (1,499-1,681)	151 (122-181)	442 (393-492)
%	100	33.1	29.5	27.2	2.6	7.6
Incidence**	57.7	19.1	17.0	15.7	1.5	4.4
Gender						
Male	61.4%	56.5%	60.6%	66.4%	69.1%	64.5%
Female	38.6%	43.5%	39.4%	33.6%	30.9%	35.5%
Incidence**						
Male	74.4	22.7	21.7	62.1	2.2	5.9
Female	42.5	15.8	12.8	29.2	0.9	3.0
Age						
Mean (*SD*)	68.1(15.4)	69.6 (15.01)	66.0 (16.8)	69.3 (14.0)	63.5 (15.8)	66.6 (14.7)
Median (IQR)	70 (60;79)	-	-	-	-	-
Age groups						
< 50	10.1%	8.7%	13.3%	7.6%	12.1%	11.4%
50-59	12.9%	12.8%	13.1%	11.1%	16.1%	14.4%
60-69	22.4%	18.7%	24.7%	22.4%	27.3%	24.8%
70-79	28.2%	27.0%	26.9%	31.2%	30.4%	27.4%
> = 80	26.5%	32.8%	22.0%	27.7%	14.0%	22.0%
Incidence**						
< 50	10.6	2.8	3.6	2.0	0.7	1.5
50-59	51.0	15.7	13.4	11.3	3.4	7.2
60-69	97.0	25.1	27.9	24.9	6.2	13.7
70-79	154.5	45.8	38.2	43.9	8.7	19.1
> = 80	216.7	83.1	46.7	58.0	6.0	22.8

Note. IQR = Interquartile range; *SD* = Standard deviation; 95%CI = Confidence intervals set at 95% for proportions; *N** = Estimated population **Estimated incidence per 100,000 inhabitants.

In the case of a new colostomy, 56.5% were men, which corresponded to an incidence of 22.7 cases per 100,000 men. In the case of a new ileostomy, 60.6% were men, with an incidence of 21.7 cases per 100,000 men. In the case of urinary stomas, 66.4% were men, with an incidence of 22.0 cases per 100,000 men. Finally, 69.1% of those with an intestinal stoma and a urinary stoma were men, which corresponds to 2.2 cases per 100,000 men.

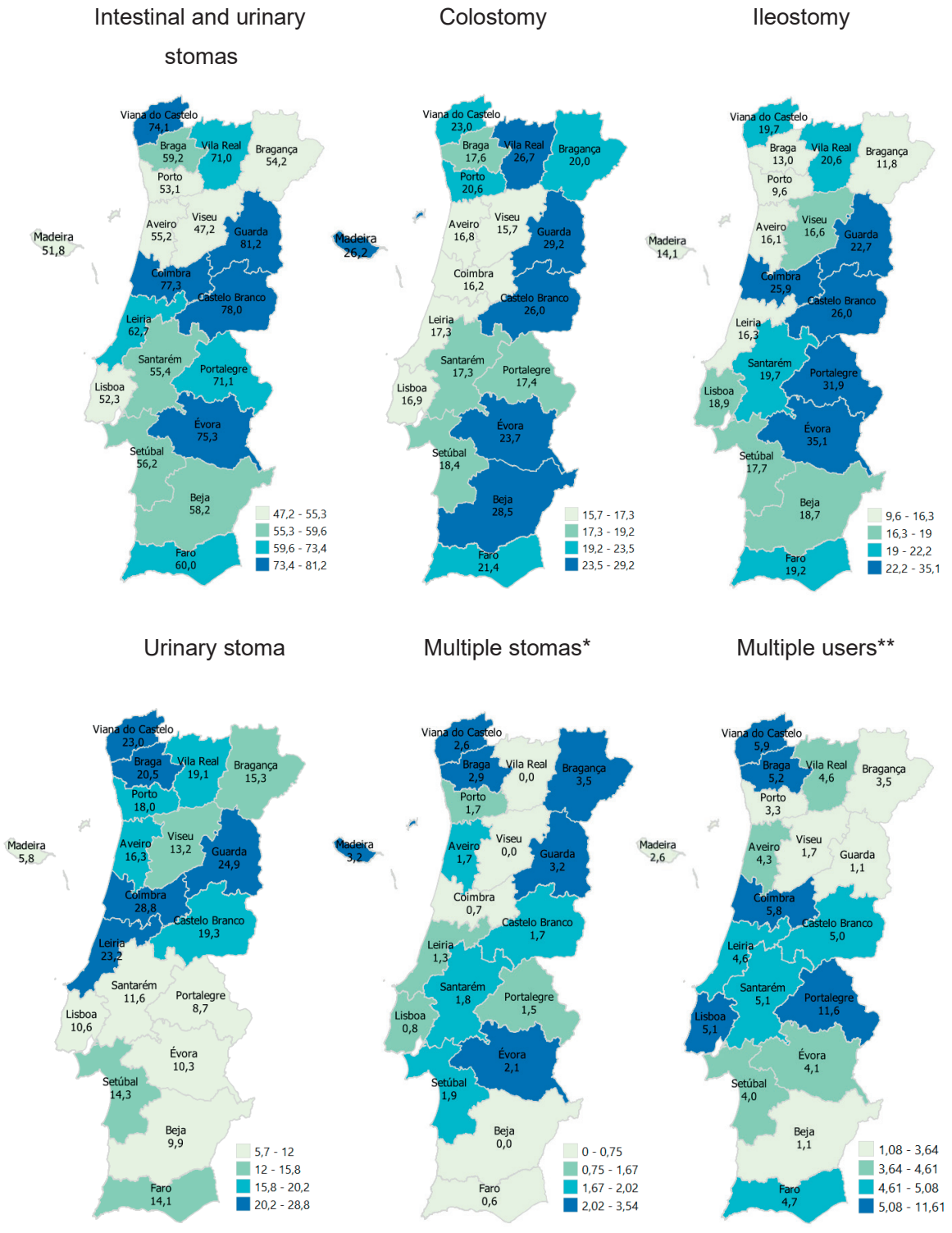
The districts of Guarda, Castelo Branco, Coimbra, Évora, and Viana do Castelo had the highest estimated incidence of people with a new intestinal or urinary stoma, ranging from 73.4 to 81.2 cases per 100,000 inhabitants, as shown in Figure 2.

In 2021, the districts with the highest incidence of colostomies per 100,000 inhabitants were Guarda, Beja, Vila Real, Madeira, Castelo Branco, and Évora, with rates ranging from 23.5 to 29.2. The highest incidence of new ileostomies occurred in Évora,

Portalegre, Castelo Branco, Coimbra, and Guarda, with rates ranging from 22.2 to 35.1. The incidence of new urinary stomas was highest in Coimbra, Guarda, Leiria, Viana do Castelo, and Braga, with 20.2-28.8 cases per 100,000 inhabitants.

Figure 2

Estimated number of individuals with a new intestinal or urinary stoma in Portugal and incidence per 100,000 inhabitants, by region and type of stoma in 2021



Note. * = People with a colostomy + urinary ostomy or ileostomy + urinary ostomy; ** = People who purchase colostomy and ileostomy appliances.

Discussion

This study presents the first nationwide estimation of the number of people living with a stoma in Portugal. The results suggest a higher prevalence of people with one or more stomas in Portugal compared to previous studies, which reported a range of 16,000 to 25,000 people (Cabral, 2009; Hospital Fernando Fonseca, 2020). This study reveals that the population requiring specialized care and services in this area is larger than previously estimated. The majority of people in Portugal with one or more stomas have an intestinal or urinary stoma, with colostomies being the most prevalent. The incidence data for 2021 confirms this trend, with colostomies being the most common type of stoma. Previous international studies have shown that colostomy is the most frequent type of intestinal/urinary stoma, followed by ileostomy (Neto et al., 2016; Sirimarco et al., 2021). These results are useful for understanding the most common types of stoma in the Portuguese population. Therefore, it may be suggested that health resources in Portugal should prioritize care circuits and professionals that specialize in caring for individuals with an intestinal or urinary stoma, particularly those with an intestinal stoma.

Regarding the sociodemographic characteristics of this population, intestinal/urinary stomas tend to have a higher prevalence and incidence in men aged 70 or older, as well as in those residing in inland Portugal for intestinal stomas or in northern Portugal for urinary stomas. It is well-known that one of the primary reasons for constructing an intestinal stoma is colorectal cancer. Risk factors for the development of this type of cancer can be demographic, genetic, or related to exposure. The most commonly mentioned risk factors in the literature include age, family history, inflammatory bowel disease, tobacco use, and dietary habits (Baidoun et al., 2021). In fact, the incidence of this type of cancer tends to be higher in men in various regions of the world (Rawla et al., 2019). This difference in incidence rates may be attributed to greater exposure to modifiable risk factors, such as alcohol consumption, tobacco use, excess weight, and dietary habits (Baidoun et al., 2021; Keum & Giovannucci, 2019). On the other hand, colorectal cancer is more prevalent in developed countries than in developing countries, with a three to four times higher incidence rate (Rawla et al., 2019). This is largely associated with a high intake of processed or red meat, saturated fats, and fats from animals, as well as preserved and seasoned foods (Aykan, 2015). This could be one of the reasons why the prevalence and incidence of intestinal stoma in 2021 was higher in inland Portugal. Accessibility and adherence to cancer screening programs may also contribute to higher values in these regions (Direção Geral de Saúde, 2022). Therefore, these results are particularly important in understanding the profile of people with an intestinal/urinary stoma in Portugal. These findings can contribute to the development of policies and care programs that are more tailored to the specific characteristics, training, and health monitoring needs of these individuals. Additionally, these findings can serve as a basis for reflecting on the prevention and screening programs for intestinal and urinary cancer established in Portugal, and how their results can be improved.

In terms of the stoma bag used, the majority favored two-piece systems with a flat base plate. Health professionals need to be aware of the available options and their indications to assist individuals in selecting the most suitable appliance based on their individual needs, characteristics, and preferences.

Lastly, it is crucial to acknowledge the limitations of this study. The study only included data from 83% of community pharmacies in Portugal, requiring extrapolation to the entire universe. Additionally, the Autonomous Region of Azores was excluded due to the lack of available data resulting from the recent implementation of reimbursement for ostomy devices through community pharmacies. Thirdly, it is important to note that the results of this study were based solely on data from the dispensation of medical devices for ostomy and not on clinical diagnoses. As a result, individuals with one or more stomas who use devices that are not identified as ostomy products or are not supplied by community pharmacies were not identified or considered in this study. Therefore, the presented results may underestimate the actual prevalence. Additionally, it was not feasible to provide a detailed characterization of the stoma type for individuals who used various devices over time. It is important to note that ostomy devices may be prescribed for reasons other than a stoma, such as managing enterocutaneous fistulas resulting from surgery. These situations may have influenced the outcome.

Conclusion

This study provides a more accurate understanding of the prevalence and incidence of intestinal/urinary stomas in Portugal in 2021, as well as the demographic and clinical characteristics of this population, including age, sex, geographic area, type of ostomy, and type of stoma bag used usage. These findings are valuable for comprehending the characteristics of individuals with an intestinal/urinary stoma and adapting monitoring programs to their specific needs. Additionally, they prompt us to consider ways to enhance intestinal and urinary cancer prevention and screening programs in Portugal. This knowledge can help optimize the allocation of specialized resources to health services in the most affected geographic areas and the training of professionals in services that serve these populations. Large-scale epidemiological studies provide evidence that supports the allocation of resources and the definition/reformation of prevention, treatment, and monitoring strategies for people with one or more stoma. In the future, it is important to provide a more detailed characterization of this population, including their education, the cause of the stoma, associated etiological factors, its duration, and their care needs.

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References

Aykan, N. F. (2015). Red meat and colorectal cancer. *Oncology Reviews*, *9*(1), 288. https://doi.org/10.4081/oncol.2015.288

Babakhanlou, R., Larkin, K., Hita, A. G., Stroh, J., & Yeung, S.-C. (2022). Stoma-related complications and emergencies. *International Journal of Emergency Medicine*, *15*, 17. https://doi.org/10.1186/s12245-022-00421-9

Baidoun, F., Elshiwy, K., Elkeraie, Y., Merjaneh, Z., Khoudari, G., Sarmini, M. T., Gad, M., Al-Husseini, M., & Saad, A. (2021). Colorectal cancer epidemiology: Recent trends and impact on outcomes. *Current Drug Targets*, *22*(9), 998–1009. https://www.eurekaselect.com/article/111592

Cabral, A. (2009). Associação Portuguesa de Ostomizados. Jornal Da Secção Regional Do Centro Da Ordem Dos Enfermeiros, 14. https://silo.tips/download/editorial-jornal-da-secao-regional-do-centro-da-ordem-dos-enfermeiros-setembro-d

Diniz, I. V., Costa, I. K., Nascimento, J. A., Silva, I. P., Mendonça, A. E., & Soares, M. J. G. (2021). Factors associated to quality of life in people with intestinal stomas. *Revista da Escola de Enfermagem da USP*, *55*, e20200377. https://doi.org/10.1590/1980-220X-REEUSP-2020-0377

Direção Geral de Saúde. (2022). *Avaliação e monitorização dos rastreios oncológicos organizados de base populacional 2021*. https://www.ffms.pt/sites/default/files/2022-07/i028766.pdf

European Ostomy Association. (2012). *Access to ostomy supplies and innovation guiding principles*. MedTech Europe. https://www.medtecheurope.org/resource-library/access-to-ostomy-supplies-and-innovation-guiding-principles-for-european-payers/

Hospital Fernando Fonseca. (2020). *Hospital Fernando Fonseca assinala o dia mundial do ostomizado*. https://hff.min-saude.pt/hospital-fernando-fonseca-assinala-o-dia-mundial-do-ostomizado/

Infarmed. (2021). *Relatório do meio ambulatório: Monitorização do consumo de medicamentos.* https://www.infarmed.pt/documents/15786/4373142/dezembro/10c6aafe-bdf6-7601-9cf3-9e-190f801531?version=1.0

Instituto Nacional de Estatística. (2021). *População residente (n.º) por local de residência, sexo e grupo etário; anual: INE, estimativas anuais da população residente*. https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_indicadores&indOcorrCod=0004163&xlang=pt&contexto=bd&selTab=tab2

International Agency for Research on Cancer. (2020). *Cancer today*. http://gco.iarc.fr/today/home

Keum, N., & Giovannucci, E. (2019). Global burden of colorectal cancer: Emerging trends, risk factors and prevention strategies. *Nature Reviews Gastroenterology & Hepatology*, *16*(12). https://doi.org/10.1038/s41575-019-0189-8

National Institute of Diabetes and Digestive and Kidney Diseases. (2020). *Urinary diversion*. https://www.niddk.nih.gov/health-information/urologic-diseases/urinary-diversion

Neto, M. Á., Fernandes, D. O., & Didoné, E. L. (2016). Epidemiological characterization of ostomized patients attended in referral center from the city of Maceió, Alagoas, Brazil. *Journal of Coloproctology*, *36*(2), 64–68. https://doi.org/10.1016/j.jcol.2014.08.016

Noordzij, M., Dekker, F. W., Zoccali, C., & Jager, K. J. (2010). Measures of disease frequency: Prevalence and incidence. *Nephron Clinical Practice*, *115*(1), c17-c20. https://doi.org/10.1159/000286345

Rawla, P., Sunkara, T., & Barsouk, A. (2019). Epidemiology of colorectal cancer: Incidence, mortality, survival, and risk factors. *Przeglad Gastroenterologiczny*, *14*(2), 89–103. https://doi.org/10.5114/pg.2018.81072

Romão, M., Figueira, D., Galante, H., Guerreiro, J., & Romano, S. (2020). Who are the ostomy patients and caregivers attending Portuguese community pharmacies? A cross-sectional study. *BMC Health Services Research*, *20*(1), 914. https://doi.org/10.1186/s12913-020-05765-7

Schultz, A., Boye, B., Jonsson, O., Thind, P., & Månsson, W. (2015). Urostomy and health-related quality of life in patients with lower urinary tract dysfunction. *Scandinavian Journal of Urology*, *49*(1), 2–7. https://doi.org/10.3109/21681805.2013.876095

Silva, K. A., Duarte, A. X., Cruz, A. R., Araújo, L. B., & Pena, G. G. (2020). Time after ostomy surgery and type of treatment are associated with quality of life changes in colorectal cancer patients with colostomy. *PLoS ONE*, *15*(12), e0239201. https://doi.org/10/gpstx3

Sirimarco, M. T., Moraes, B. H., Oliveira, D. R., Oliveira, A. G., Schlinz, P. A., Sirimarco, M. T., Moraes, B. H., Oliveira, D. R., Oliveira, A. G., & Schlinz, P. A. (2021). Thirty years of the health care service for ostomy patients in Juiz de Fora and surroundings. *Revista do Colégio Brasileiro de Cirurgiões*, *48,* e20202644. https://doi.org/10.1590/0100-6991e-20202644