

Narratives of Life: Understanding the Viability of Digital Storytelling as a Breast Cancer Patient-Centred Care Tool for a Caring Future in EU-27 Countries

Renata Maia Arezes^{1,2*}, Joana Quental^{3,4}, Anabela Pereira⁵, Raquel Guimarães⁶

^{1,3} DeCA, Department of Communication and Art, University of Aveiro, Portugal

^{2,4} Research Institute for Design, Media and Culture (ID+), DeCA, University of Aveiro, Portugal

⁵ DEP, Department of Education and Psychology, University of Aveiro, Portugal

⁶ São João Hospital Breast Centre, Porto, Portugal

* Corresponding author's email: arezesrenata@gmail.com

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ABSTRACT

The present study addresses the viability of digital storytelling in Patient-Centred Care as a contributing tool to psychological wellbeing and social cohesion in European Union 27 countries (EU-27). Storytelling is regarded as an important tool for medical practice, promoting the development of coping mechanisms and empowerment in patients. The future of healthcare is increasingly digital, moving towards new paradigms of care that benefit the patient through customized and dedicated tools, allowing for tailored health instruments that may give an overall increase in health improvement and maintenance, through support, monitorization or at distance care. In this context, digital storytelling arises as a natural result from the adjustment of a widely used and approved method to a new technology, with recognized benefits of powerful engagement. Through data analysis on digital access, digital literacy, and digital skills among population in EU-27 countries, we focus on the viability of storytelling through digital tools regarding social-economic factors. Analysis is narrowed to women, since our main field of work is on female breast cancer. Data analysis shows the existence of a gap on digital literacy between EU-27 countries, suggesting a correlation between patient context and effectiveness and usage possibility of digital tools. Although digital storytelling may represent the future as a contributing tool to psychological wellbeing, the difference between and within EU-27 countries shows that there are still fundamental issues concerning digital literacy and full accessibility that must be addressed before this tool may assume a main role in detriment of analogical approaches, regarding equity and democratic access to healthcare.

Keywords: Digital Storytelling, Digital equity EU, Healthcare.

1 Introduction

All 27 European Union countries (EU-27) are currently classified as developed economies by the United Nations (UN) [1]. According to the UN, development implies a higher quality of life for people [2]. This affects not only life expectancy, which is steadily increasing in Europe since 1960, although with a small decline since 2020 in 23 of 27 Member States due to the effects of COVID-19 pandemic [3][4], but also healthy life expectancy [5], an important indicator of population's health. As life expectancy increases, the overall number of people suffering from chronic illnesses such as cancer also rises. Breast cancer is by large the most common cancer in women in the EU-27. According to statistics, it represents almost 30% of all cancers in this group (374 836 women) in 2022, with a death rate of 16,7% compared to all cancer sites (116 979 women), the highest between the most common cancers in this sex group, even though with an higher age-specific 5-year relative survival [6][7]. Even though mortality rates are decreasing by the year [8] due to health policies that are increasing early diagnosis methods' implementation along with new



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treatments, and the estimated incidence in 2040 suggests a decrease of 1,5% when compared to 2020 values (from 28,7 to 27,2%), mortality rates are still high, predicting only a 0,2% difference between 2040 and 2020 values (from 16,5 to 16,3%) [9]. Converting these values to numbers, the perspective is not so optimistic, since they represent an increase of 355 457 to 390 056 women affected by breast cancer, and 91 826 to 114 774 deaths from 2020 to 2040 in EU-27 baseline projected population. Social-economic factors in developed economies such as the decrease of Gross Domestic Product (GDP) growth and employment rates (in some EU-27 countries), annual inflation increase, and the almost stagnation of economic growth might also contribute to aggravate the estimated numbers of breast cancer cases and mortality [10][11].

In EU-27, breast cancer has an incidence of 54% in women aged between 45-69 years, 35%, in women with 70+, and 11% in women aged between 20-44 years (the number of cases in women aged 0-19 years is almost inexpressive) [12] (Figure 1). Countries in the EU show a rapidly aging population and women's age at birth of first child increase, factors that may contribute to a further increment in breast cancer cases [13] [14] [15]. The impact on public health promotes the search for new and more efficient methods and tools for healthcare systems sustainability.

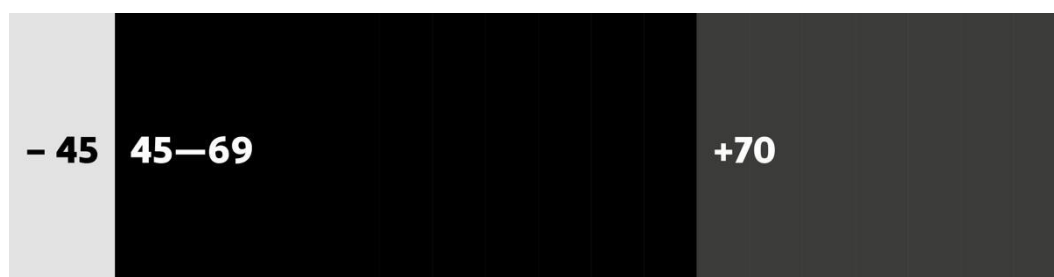


Figure 1: *Breast Cancer incidence in EU-27 by age (women). Source: ECIS.*

The future of healthcare is increasingly digital, moving towards new paradigms of care that benefit the patient through customized and dedicated tools, allowing for tailored health instruments that may increase health improvement and maintenance through support, monitoring, or at-distance care [16]. In healthcare, storytelling is regarded as an important tool for medical practice when addressing emotional and psychological well-being and is widely used in practice like psychotherapy. Through resourceful written and presented stories, storytelling may promote the development of coping mechanisms and empowerment in patients, with recognized benefits in chronic illnesses treatment as a Patient-Centred Care tool [17]. In modern societies, progressively turning towards the digital era, digital storytelling arises as a natural result of a widely used and approved method adjustment to new technology and possibilities, along with the exploration of powerful patient engagement's increasing benefits. But is this transition possible and desirable in EU-27 countries? How do we talk about digital access, digital usage, digital literacy, and digital skills among the different countries that make up this community? To understand the universal viability of digital tools, this work takes a deeper look at EU-27 countries, through literature, information, and data presented in relevant databases — Eurostat [18], ECIS [19], INED [20].

2 Methods

This work uses three major databases as main data source. For data on households, population, educational level, and individuals, the primary source of information was Eurostat, the statistical office of the EU that provides statistics at a European level, through the European Statistical System (ESS). This allowed comparisons between EU-27 countries on households' level of internet access and broadband internet coverage by speed, population by age group and sex (2022), population current activity status, educational attainment level (2021), individual's level of overall digital skills (2021-), individual's frequency of internet

use (2022), individuals’ devices used to access the internet (2021), individuals’ internet activities (2018-2022). The analysis was made using the most recent data, according to database’s availability.

For data on breast cancer incidence, mortality and survival across Europe, the main source of information was ECIS – European Cancer Information System, scientifically and technically developed by the European Commission's Joint Research Centre (JRC) in collaboration with the Directorate-General for Health and Food Safety (DG SANTE), and the cooperation of cancer registries associated to the European Network of Cancer Registries (ENCR). ECIS’ estimates of age-adjusted female breast cancer incidence and mortality rates are standardized using the new European Standard Population (ASR). For survival, ECIS includes the results of the latest EURCARE study (EUROCARE-5) [21]. Only female breast cancer data was considered, since its incidence disease in male population is rare and almost inexpressive. Data on demographic and social-economic prospects — life and healthy life expectancy, GDP, employment rates, inflation variance and economic growth in developed economies — was collected from INED - Institut National d’Études Démographiques, a French public research organization specialized in the study of populations, and United Nations (UN), through the Department of Economic and Social Affairs’ economic analysis (2022/2023).

3 Results and Discussion

3.1 Households

Generally, in the EU-27 level of internet access in households can be considered good as all countries show results above 85%, with an average of 92,5% (Figure 2) [22]. A clear co-relation with GDP is visible since countries with a lower GDP per capita show lower levels of internet access than wealthier countries [23]. The chart shows us the disparity in internet access in households, interestingly highlighting quite a few disparities and similarities between some countries: Cyprus, Estonia, Poland and Latvia, show levels close or even above the average in spite of their lower GDP per capita when compared to other countries in this group; on the contrary, Germany, a country with a higher GDP per capita shows levels below the average; Finland and Spain, with similar results even though with largely distant GDP per capita values.

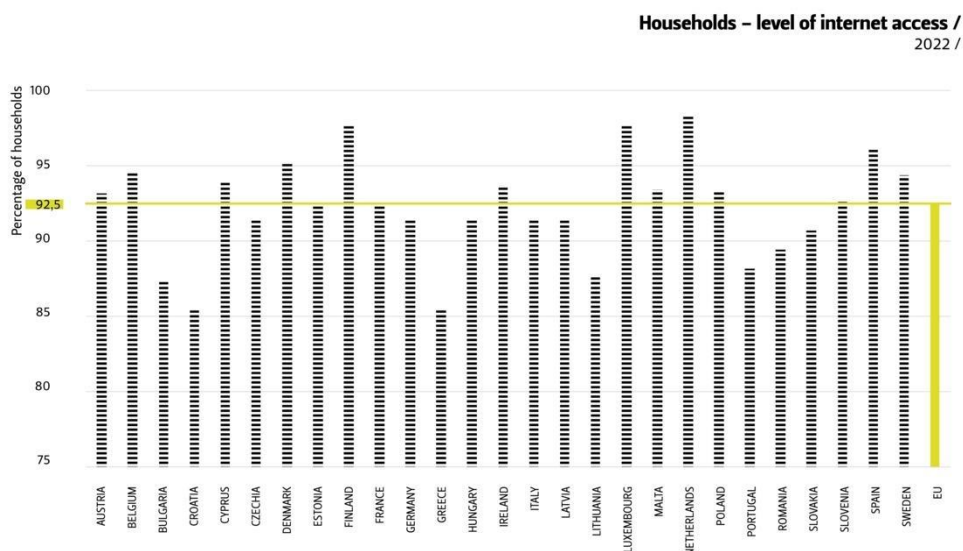


Figure 2: Households, level of internet access. 2022. Source: Eurostat.

EU-27 countries with more households with no internet access at home [24] due to high costs of the service or equipment in 2019 (Figure 3) are generally the ones with lower GDP per capita. Higher percentages belong to countries like Portugal, Bulgaria, Croatia, Hungary, Cyprus, Romania, Greece, and Malta, but surprisingly also to France. The average percentage in the EU-27 is around 3%. Even if this seems almost

irrelevant, it is important to consider the number of people impeded from internet access represented by this value.

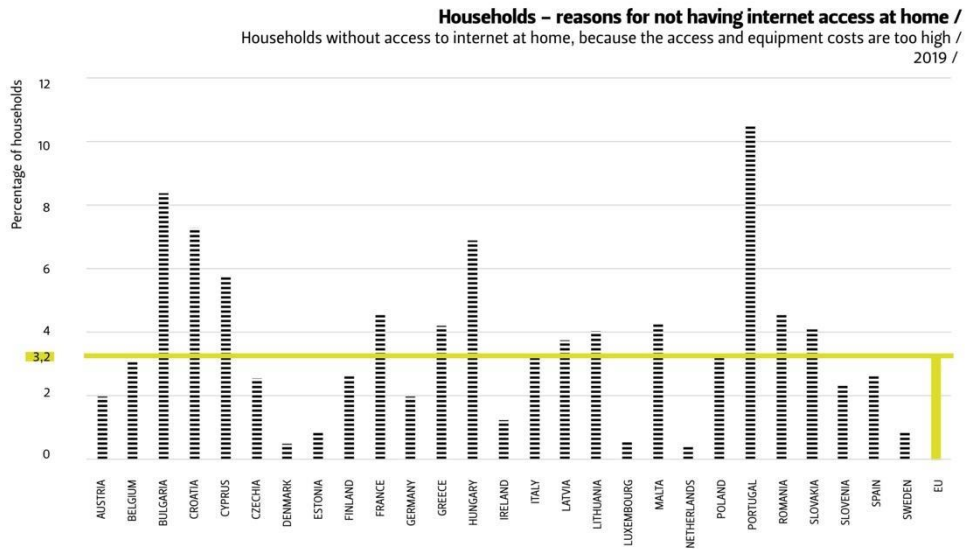


Figure 3: Households, reasons for not having internet access at home (I). 2019. Source: Eurostat.

There are also other reasons for not having internet access in households, either because it is not needed, since people already have access in their work or other facilities, or because they consider that the content is not useful or interesting. Looking at the latest through numbers (Figure 4), we can see interesting results regarding countries with different GDP per capita values. The average percentage in the EU-27 is right below 50%. It is relevant to look at this number as the result of an individual choice.

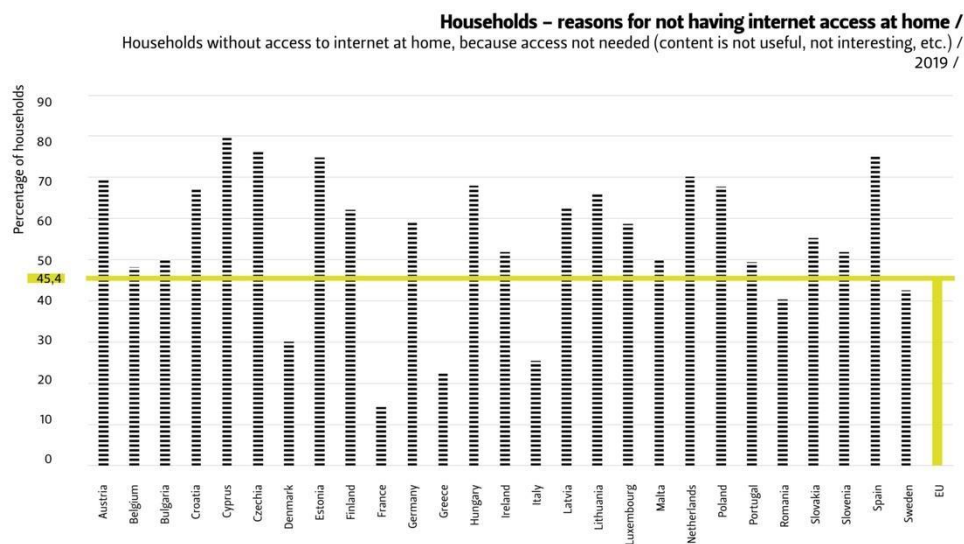


Figure 4: Households, reasons for not having internet access at home (II). 2019. Source: Eurostat.

Looking at broadband internet coverage by speed in each country and considering more than 1 gigabit per second (Figure 5), the average stays above 60%, once again contradicting the expected results in countries with lower GDP per capita (e.g., Portugal) [25].

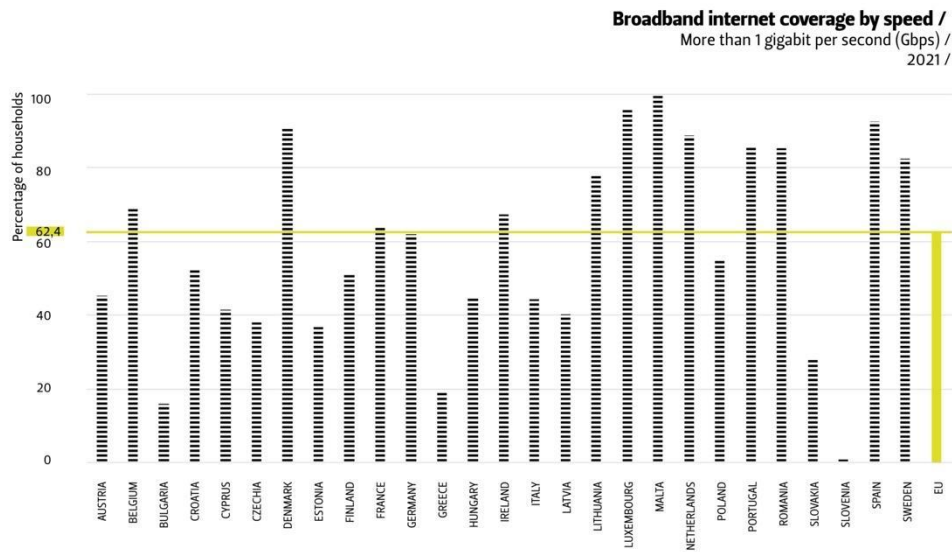


Figure 5: Broadband coverage by speed. 2021. Source: Eurostat.

Summing up, EU-27 households have averages of 92,6% level of internet access; 3,2% have no access to internet at home because of access/equipment’s high costs, and 45,4% because access is not needed; and 62,4% have broadband internet coverage above 1 Gbps.

3.2 Individuals

This work focuses on female breast cancer. Since in the EU-27, male and female populations are similar in numbers by age group, results will be read for the total population by sex as similarly representative of the female population. Dividing the total female population into age groups related to breast cancer incidence, we can see how which group is represented in each country — 20 to 44 years old, 45 to 69 and plus 70 (Figure 6) [26]. The largest age group at higher GDP per capita countries corresponds to females aged between 45-69, the same with higher breast cancer incidence (Figure 1).

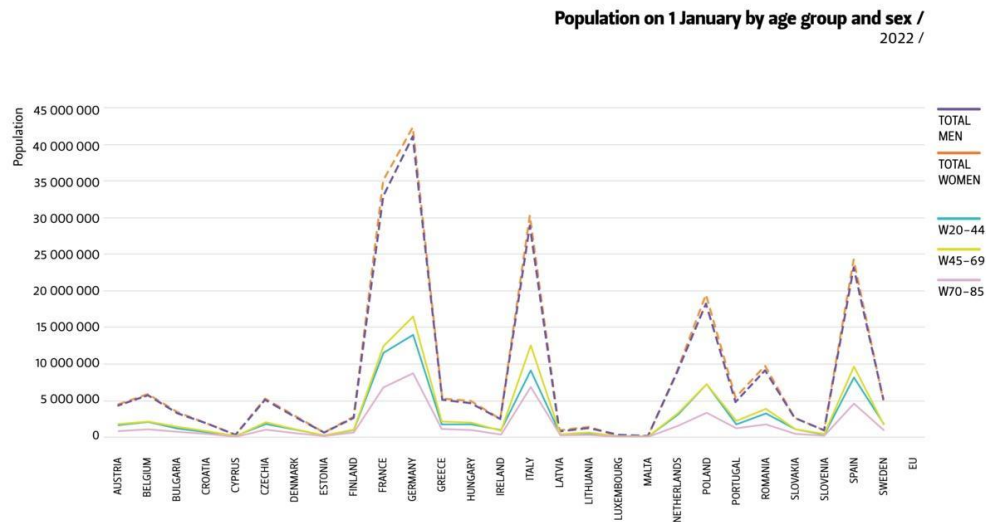


Figure 6: Population, by age group and sex. 2022. Source: Eurostat.

Comparing EU-27 countries population by educational attainment level (Figure 7) it is visible that all countries show high levels of education with all ISCED levels (up to bachelor's degree or equivalent), with numbers above lower levels of education [27].

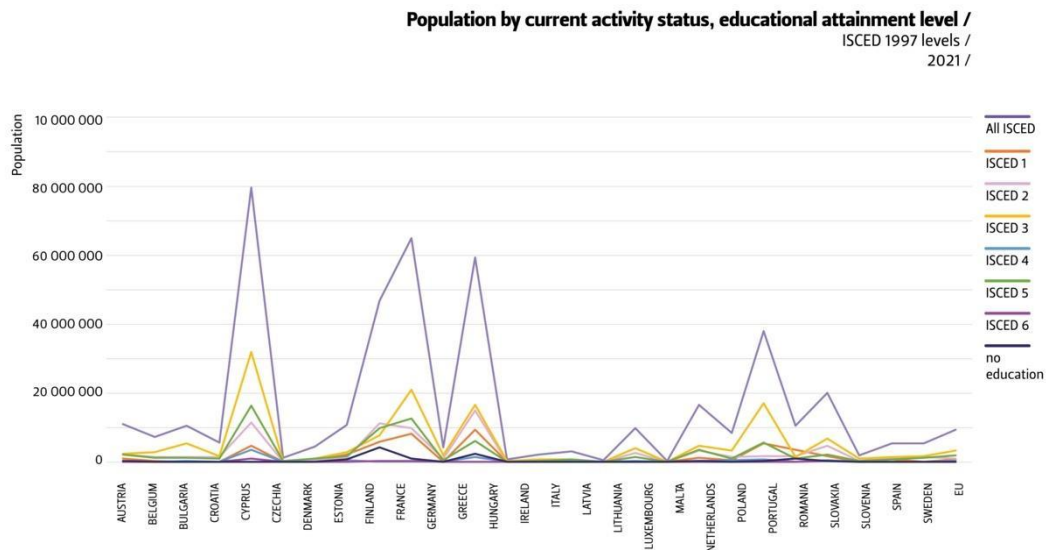


Figure 7: Population, current activity status, educational attainment level. 2021. Source: Eurostat.

Concerning individual's level of overall digital skills (Figure 8), EU-27 countries show higher percentages of individuals with basic or above basic overall digital skills, rather than individuals with no overall digital skills [28].

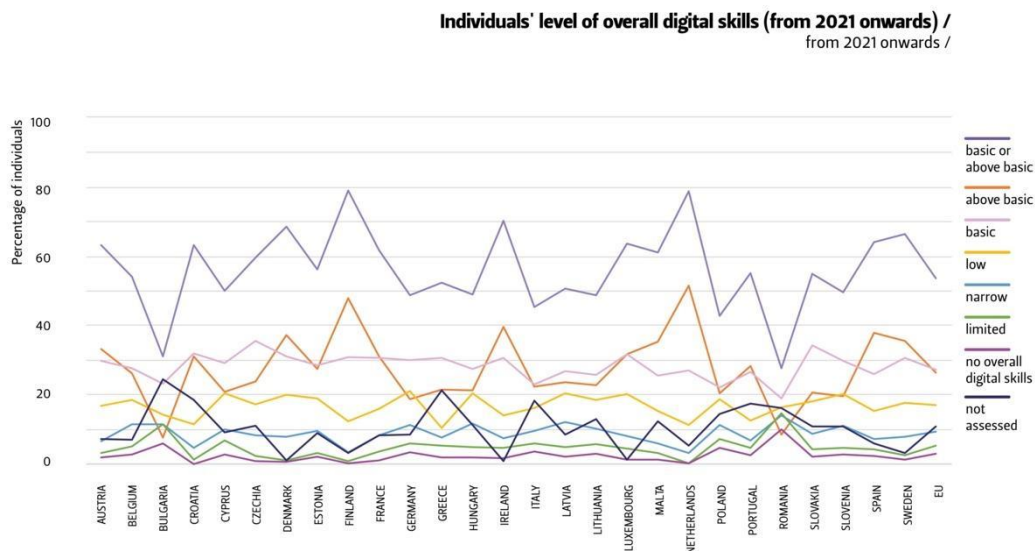


Figure 8: Individuals, level of overall digital skills. From 2021 onwards. Source: Eurostat.

Regarding individual's frequency of internet use (Figure 9), once a week and daily represent the higher percentage in all the EU-27 countries [29].

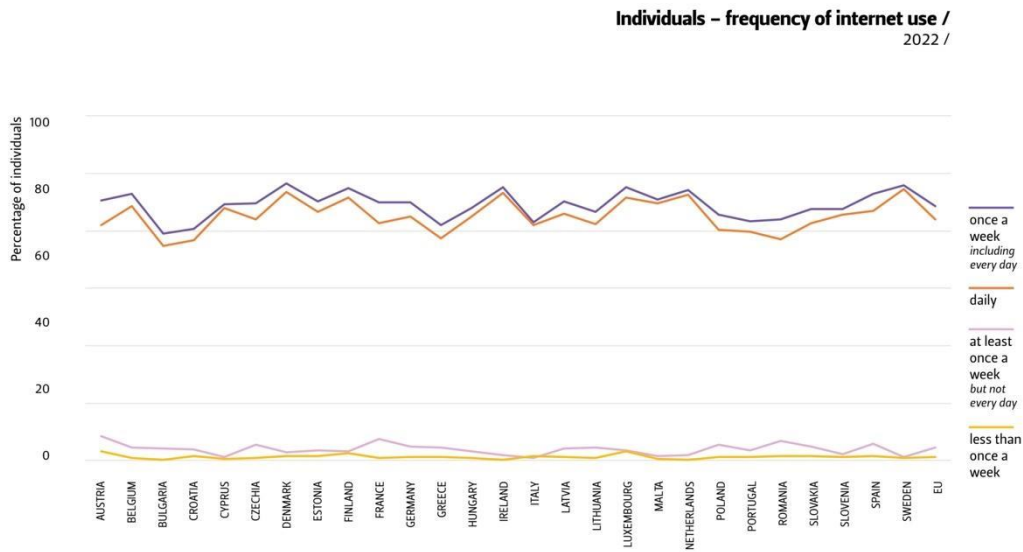


Figure 9: Individuals, frequency of internet use. 2022. Source: Eurostat.

In EU-27 countries, numbers show us that internet access is mainly made by mobile devices rather than by laptop or desktop computer and that among the first, smartphones are by large the preferred device when compared to tablets or other mobile devices (Figure 10) [30].

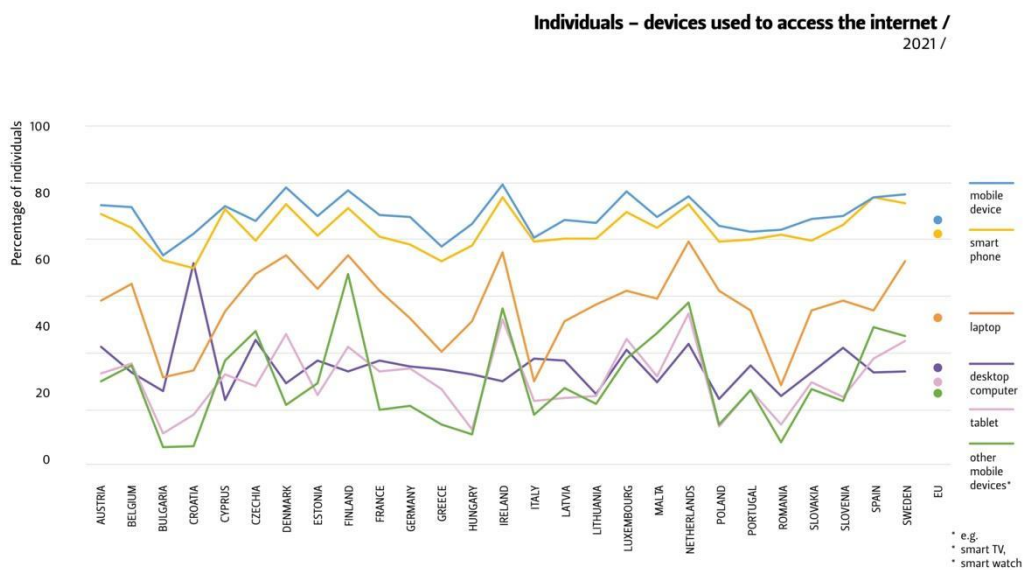


Figure 10: Individuals, devices used to access the internet. 2021. Source: Eurostat.

Finally, looking at individual's internet usage on seeking for health information (Figure 11), there is an interesting correlation between levels of higher education and health information seeking, suggesting a ratio between education, science recognition and patient activation [31]. The average progression in the EU-27 countries between 2018 and 2022 shows a small decrease from 2019 forward, contradicting the increasing tendency observed since 2013 that can be related to the Covid-19 pandemic.

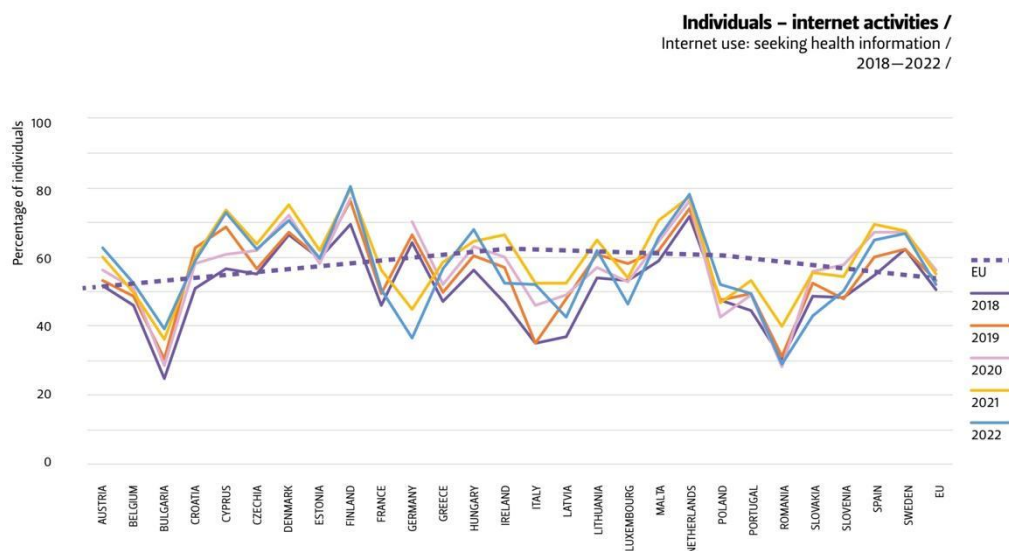


Figure 11: Individuals, internet activity, seeking health information. 2018-2022. Source: Eurostat.

Summing up, when relating to age and sex, individuals in the EU-27 countries with higher GDP per capita status have the highest percentage of women aged between 45-69, the age group with higher breast cancer incidence; on education, all countries have a higher percentage of individuals with all ISCED 1997 levels; digital skills are basic or above basic on more than 50% of the population in each country; internet is used mostly daily through mobile devices/smart phones; and internet use specifically on health information is above 50% in all countries.

4 Conclusions

Even though the overall numbers represent above average and promising numbers of connected and digitally skilled and educated individuals, there is still a relevant gap between EU-27 countries. Data shows that developed countries with higher GDP per capita are those with better internet connections and usage. These countries also have the higher rates of breast cancer incidence. Digital storytelling is then not only medically required as a healthcare tool for chronic illness treatment, but here it finds the right environment to exist and evolve. Furthermore, it may also function as a social cohesion tool in developed societies where the ancient practice of storytelling as a universal source of knowledge, insight, and awareness is getting lost due to crescent individuation, isolation, and family disintegration. The digital means' universalization replaces this core tool in the centre of society, allowing people to regain access to metacognition by looking upon stories for example, inspiration, guidance, or assurance. This represents a promising opportunity for integrating digital storytelling as a Patient-Centric Care tool in breast cancer treatment. Customization through Human-Centred Design is advised for higher efficiency rates based on different patient needs and cultural contexts. Although digital storytelling may represent the future as a contributing tool to psychological well-being, the data shows that fundamental issues concerning digital literacy and full Internet accessibility must be addressed when regarding equity and democratic access to healthcare before digital storytelling may assume a main role in detriment of analogical approaches in EU-27 countries. And yet, although looking for a future where people can have access to equal opportunities regarding the digital world when relating to everyone's own needs, capabilities and unique socio-cultural background, equity should be pursued as the right to be different, offering the same opportunities to both digital and analogical tools' users, no matter the disparity between both.

5 Declarations

5.1 Acknowledgements

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5.2 Competing Interests

The authors declare no conflict of interest.

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