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EDITOR'S NOTE

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Introduction

- 1 Organ transplantation is a life-saving operation. Yet, organ shortage is a worldwide problem, as the demand of organ transplantation exceeds the supply of organs. Information about organ donation is provided through various means, such as leaflets, internet, talks from professionals to inform the public about important decisions on their health and wellbeing. This is often facilitated through health literacy. Different countries have variation in organ donation rates suggesting differences in the delivery and approach of health literacy delivery this paper aims to review.

1. Health Literacy

- 2 In a world of continuous information flow, relying on accurate health information is of critical importance to our life. The COVID-19 pandemic clearly shows that reliable and easy to understand health information can save lives (Abel &McQueen, 2020). Especially during times of health crises, we need to revisit the importance and role of health literacy in our life.

1.1 Health Literacy Scope

- 3 In the 1990's, the term referred mostly to the patient adherence to the medical instructions (Ad Hoc Committee on Health Literacy, 1999). Later, it focused on reading skills and understanding of written health information, such as consent forms (Kickbusch, 2001). Progressively, health literacy was studied more under the perspective of health promotion (USDHHD, 2000). Health literacy, according to the Calgary Charter (Coleman et al., 2008, p.1), is 'the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives.

These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills’.

- 4 Health literacy also influences decision-making. Basing our decisions on reliable information, understanding and weighing the pros and cons of health-related behaviour, ensures that the decisions are based on consideration and reflection on different factors rather than spontaneous and uninformed choices. This knowledge base of health-related information when combined with critical thinking, filters the information and can become a source of empowerment (Sykes, Wills, Rowlands, & Popple, 2013). When individuals know their rights and recognise the change that needs to take place regarding situations and policies, then they can take action to restore the inequalities. It becomes a matter of civic responsibility to work with other community members to address the health issues which are important to them (Kickbusch & Maag, 2008).
- 5 Besides looking health literacy at individual level, it is crucial to look at the health literacy at organisational level, as this would help benefit especially the health literacy needs of vulnerable groups, such as the elderly and ethnic minority groups (Kutner, Greenburg, Jin, & Paulsen, 2006; Roberts, 2015). The Institute of Medicine (Brach et al., 2012) suggested that health organisations could become health literate by adopting ten attributes, such as involving populations in the design, evaluation and quality improvement of policies and measures, providing assistance in the navigation of health systems, easy access to information and designing materials which can be easily understood by the users.

1.2 Tailoring health information messages

- 6 The delivery of a message has to ensure that the information has certain characteristics that make it pertinent to the receiver and help them to take appropriate action (Anderson, Leister, & Rego, 2020). As health information addresses all people irrespective of their educational level and health literacy levels, the content of information needs to be easily understandable for all. The Health Literacy Precautions Toolkit (DeWalt et al., 2011) recommends practices which could help reduce complexity of information. Based on these recommendations, Brega et al. (2015) discussed that readability was the main characteristic of health-related information, ensuring that the reading material level corresponded to fourth to eleventh grade. They also suggested that less attention is paid to further characteristics of engaging reading materials, such as understandability, which allow readers to explain key messages, and actionability, which ensures that readers can identify the self-care actions suggested in the reading material.

1.3 The role of the Internet in health information

- 7 In recent years, people of various ages and backgrounds turn to web-based resources to access a plethora of information, making the Internet a potential medium of enhancing health literacy (Christmann, 2005). The use of the Internet as a source of health information is steadily increasing over the years. The 2003 Eurobarometer report (European Opinion Research Group, 2003) showed that 23.1% chose the Internet to get information about health, while 41.5% believed that Internet is a good source of

information and of younger people (55.7%) had more positive attitude towards Internet compared to 26% respondents over 55 years old.

- 8 Over a decade, the use of the Internet as a source of health information broadened. In the 2014 Eurobarometer report (TNS, 2014), conducted in the 28 Member States of the European Union, 59% searched the Internet to get health-related information and 77% expressed the opinion that the Internet is a good tool for health information. The respondents of people over 55 years old who had positive attitude towards the Internet, was 63%, which although lower than that of younger people (82%-86% dependent on the age group), showed that the Internet was more accessible for older people than it used to be in previous years. Another survey in Japan (Ishikawa, Kato, & Kiuchi, 2016), showed that newspapers and the Internet are preferred as sources of health information by people with higher health literacy levels.

2. Organ Donation

- 9 Organ transplants can dramatically improve the quality of life of patients with disabling diseases, but it can also be a life-saving treatment for patients with terminal organ failure. According to data from the Global Observatory on Donation and Transplantation (World Health Organization, 2020) activity of 86 member states in 2018 showed that about 146,840 solid organ transplants were performed worldwide. Although there was a 6% increase of transplants compared to 2017, the global needs exceeded around 10%. Part of the solid organ transplants were performed due to living organ donors: 36% living kidney transplants of the 95,479 kidney transplants performed and 19% living liver transplants of the 34,074 liver transplants performed and overall there were 39,357 deceased donors.

2.1 Organ Donation in different countries

- 10 The rates of transplantation significantly vary between regions and countries. According to data from the International Registry in Organ Donation and Transplantation (IRODaT, 2019), in 2019 Spain's rate of 49 actual deceased organ donors per million population (pmp) was the highest rate worldwide, and followed the USA with 36,88 deceased organ donors pmp, Croatia with 34,63 pmp and Portugal with 33,8 pmp.
- 11 However, a discrepancy takes place as the organ waiting lists get longer, while the transplants do not increase at the same rate. The result of this discrepancy between the number of donors and the number of transplanted organs is organ shortage. In 2019, in the USA 112,568 patients were registered on waiting lists, while 39,718 transplants took place (<http://www.optn.transplant.hrsa.gov>). A second example comes from the data regarding Europe. In 2018, according to the Council of Europe (www.coe.int) 150,000 people were registered on waiting lists although 41,000 patients were transplanted.
- 12 The differences of rates could reflect different approaches to deceased organ donation among countries (Meyer, 2019). A recent study (Becker et al., 2020) of interviews with 17 experts working in transplant centers from Austria, Germany, Spain and the UK showed differences and similarities in the healthcare systems as well as the communication strategies. Regarding communication, the issues of family approach, family discussions and media coverage stood out. There was general agreement that at

a hospital, family should be approached by trusted members of staff. The impact of media reports was also seen as important in establishing the public's trust in the transplantation system. Bad media reports or low visibility of transplant cases was seen as affecting family refusal rates. Consensus was high on the importance of transparency in organ donation process and raising public awareness. It was also noted that although an opt-out system would raise discussions within families, the introduction of such a system would not be adequate on its own in raising organ donation rates.

- 13 There is a wide range of resources on raising awareness and educating people on organ donation. One of these readily available resources is the national websites of countries on the topic of deceased organ donation (DOD). This paper looks to review the scope of information that is covered and the gaps that need to be addressed in the official websites about organ donation in three European countries with differing organ donation rates. The IRODaT data (2019) showed that Spain had the highest organ donation rates, followed by the UK and the Netherlands.

3. Method of research

3.1. Theoretical Framework

- 14 Mass communication is often assessed through cross-comparative content analysis. This is subsequently utilised to extract key themes, sub-themes (White and Marsh, 2006). This discipline stems from social marketing target analysis frequently employed by healthcare organisations such as the World Health Organisation to evaluate health learning materials (Mannoff, 1985).

3.2. Data Collection

- 15 We examined the National Health Service Blood and Transplant (NHSBT) in the UK; the Netherlands Transplantation Society (NTS) in the Netherlands and Organización Nacional de Trasplantes (ONT) in Spain. The national websites inform the public about figures of DOD in their country, arguments to support DOD, registration options and ways to engage and raise awareness. They offer various sections of information and motivate the public to make an informed decision about organ donation. The review of the content of the websites of NHSBT, NTS and ONT was conducted in the period 2014-2016 using thematic analysis. Thematic analysis is suitable for interdisciplinary research and helps to the identification, analysis, organisation, description and report of themes in a set of data (Braun & Clark, 2006; Nowell, Norris, White, & Moules, 2017; Pope, Ziebland, & Mays, 2000). It is flexible, as it is a method not linked to a particular epistemological perspective (Maguire & Delahunt, 2017). It helps organise data in a way that similarities and differences become clearer and themes and sub-themes emerge. The collection of data and the analysis of their content was conducted in the ATLAS.ti.8 software, facilitating the handling and organisation of data. The common themes for all three websites were identified on ATLAS.ti8 and subthemes were extracted to explore a topic more fully. The coverage of each theme/subtheme was stratified in 1 of 5 categories. 'Not present' was the least/ not covered in the website, 'Sentence' signified basic coverage, 'Paragraph' indicated basic/moderate coverage, 'Subsection' indicated moderate to advanced coverage and 'Further Links' advanced extensive coverage.

3.3. Data Processing

- 16 The Dutch NTS and Spanish ONT websites were translated into English using online automated translation directly mirroring the information utilised by the public that uses the website and requires translation. Nevertheless, the online translation algorithm has a margin of error introducing inaccuracies in translation especially in specialist terms. In effect, the collaborators for the Netherlands and Spain (FD, DC respectively) assessed the accuracy and suitability of the translation and offered clarification in any ambiguity.

4. Results of the comparison of three Official Websites about Organ Donation

- 17 The three websites present a wide array of information regarding DOD. Using the format of 'Questions and Answers' they aim at being easily accessible and understandable by people of various health literacy skills. Graphic elements, such as video animations, infographics and videos of transplant recipients, especially in the NHSBT and NTS websites, present in a direct way difficult concepts, while also aim at making more relatable the content of the information.
- 18 Our analysis revealed five themes in all three national DOD websites which we will present more in depth: personal values, facts about the process, registration options, family communication and promotional resources.

4.1. THEME 1: Personal Values for Organ Donation

- 19 The websites promote values which support the organ donation (**table 1**). The most prominent values were empathy, reciprocity and social responsibility, autonomy, religious and spiritual endorsement, which we will further present.
- 20 The UK website, NHSBT, presented the values of reciprocity and empathy as central to organ donation, by asking its visitors if they would receive an organ, in case they needed it.
- 21 The Spanish website, ONT, focused on the value of solidarity in society. It attributes the success (highest rate of organ donors pmp, as mentioned earlier) of the Spanish model to a degree to the solidarity and the altruism which the people have been showing.
- 22 The Dutch website, NTS, tried to tackle the objections of sceptical people who needed more information on the topic. Through questions, answers and quotations of lay people, it provided information which was critical for decision making. The emphasis was not so much on the social responsibility but on the personal autonomy, as each person has to approach this topic by finding the answers which ease their concerns and build personal links to the issue of organ donation.
- 23 The websites of NHSBT and NTS also present the views of religious and spiritual figures on the topic. They aim at explaining that there are no controversies between the main religions and the act of organ donation, not interfering with the teachings of their faiths, valuing the gift of life, respecting the sanctity of the body and being rewarded as

acts of kindness. More details on the standpoints of the main religions are provided on the two websites.

Table 1 - CROSS COMPARISON OF THE WEBSITES REGARDING DOD IN THEME 1: PERSONAL VALUES

FEATURES	THEME 1: Personal values and DOD		
	NHSBT	NTS	ONT
Social responsibility	Subsection	Subsection	Further links
Pro-donation values	Further links	Further links	Further links
Addressing uncertainty	Subsection	Further links	Sentence
Religious perspectives	Further links	Further links	Sentence

4.2. THEME 2: Facts on the Organ Donation Process

- 24 This theme was the biggest one containing several aspects, from medical to legal. Therefore, it was broken down to the sub-themes of organ shortage, waiting lists, eligibility criteria, protocols in hospitals and death (**table 2**).

4.2.1. Subtheme 2.1: Organ Shortage

- 25 The first sub-theme covered the problem of organ shortage. The severity of the topic is highlighted either as a negative issue which needs to be addressed or as a positive action of raising the rate of organ donors and transplants.
- 26 The NHSBT website explains the severity of the issue through statistics and graphical data. It also emphasises the need of organs among the Black, Asian and minority ethnic groups (BAME).
- 27 The NTS website also covers the issue presenting statistics and emphasising the need for people to register as donors. On the other side, the ONT website does not insist on this information, but presents the success of the 'Spanish model' which has achieved higher rates of organ donation and transplants than other countries.

4.2.2. Subtheme 2.2: Waiting Lists

- 28 Information on the waiting lists was available on all three websites, with the main feature being that they are regulated according to medical criteria and are not biased. The NHSBT website also provides information on lifestyle changes, such as smoking cessation, which recipients need to sustain before transplant.
- 29 The ONT website explains the three criteria under which patients are evaluated. These criteria are the territorial criterion which looks at the recipient and the organ being in the same region to reduce the ischemia time; the severity criterion which prioritises patients at a national level; and the clinical tests criterion, which evaluates the match between the recipient and the donor. The NTS provides information and statistics on the organs which are transplanted.

4.2.3. Subtheme 2.3: Eligibility Criteria

- 30 The NHSBT website refers to the age criterion of donors. It explains that for cornea donation the upper limit is 80 years old, while for heart valves and tendons the upper limit is 60 years old. There is no reference to upper age limits for organs. When it comes to lower age limits, it specifies that children can be organ donors, but their parents or guardians need to give consent. It also refers to some medical conditions, which may interfere with the organ donation, such as cancer and HIV/AIDS. Specifically, for potential donors with the condition of HIV/AIDS it is clarified that they can donate organs to recipients with the same condition. It is also reminded that the medical teams evaluate each case to see how the eligibility criteria are applied. The NTS website refers to the lower age criterion of 12 years as well as the criterion of mental competency.

4.2.4. Subtheme 2.4: In-hospital Protocols

- 31 The three websites explain that the medical teams follow strict protocols at all times. NHSBT, NTS and ONT all refer to the relevant legislation, and external regulatory bodies. They make clear that the medical teams treat all patients with the same standards irrespective of whether they are potential donors or not.
- 32 While NHSBT provides multiple links regarding legislation, the NTS website explains in depth the process of organ donation request. It describes the stages from identifying a potential donor in the intensive care units through multiple tests to the retrieval surgeries.

4.2.5. Subtheme 2.5: Death

- 33 The topic of death is inherent in the concept of Deceased Organ Donation and could not go unaddressed in the websites. The NHSBT and ONT discuss the criteria of inclusion and exclusion of a potential donor. The NTS website, though, provides more details on the differences between circulatory and brain death, as well as when the family can say 'goodbye' after the organ donation as well as the potential funeral arrangements.

Table 2 - CROSS COMPARISON OF THE WEBSITES REGARDING DOD IN THEME 2 (FACTS ON THE DOD PROCESS)

FEATURES	THEME 2: Facts on the DOD process		
	NHSBT	NTS	ONT
The Organ Shortage issue	Further links	Further links	Subsection
Waiting lists	Further links	Further links	Further links
Eligibility criteria	Further links	Further links	Sentence
In-hospital protocols	Subsection	Further links	Paragraph
Death	Further links	Further links	Sentence

4.3. THEME 3: Registration Options

- 34 This theme is further categorised into the subthemes of formal registration, amendment of decision and legislation.

4.3.1. Subtheme 3.1: Formal Registration

- 35 All three websites provide clear information on registration options and process (**table 3**). The information which they had provided up to that point, aimed at helping the visitors of the websites to contemplate the issue. The registration information addresses those who are ready to take action and move from being 'passive' supporters of organ donation to 'active' registered potential donors. Hyperlinks guide the visitors to the electronic organ donation registers. In the NHSBT website, the registration options are available at several parts of the website, probably to address the needs of the visitors who have already made up their mind and are ready to register through the website.

4.3.2. Subtheme 3.2: Decision Amendment

- 36 The NHSBT and the NTS websites direct with hyperlinks the visitors to the option of amending their registered decisions.
- 37 The ONT website explains that the organ donation card holders need to communicate their new wish to their family, so that they are aware, and, in case of organ donation request, they can inform the medical teams. It also informs that the information is not stored in an official register and, therefore, it is personal responsibility to inform about wishes.

4.3.3. Subtheme 3.3: Selective and Living Donation

- 38 All three websites inform their visitors of the organs and tissues which can be donated and transplanted. The ONT also encourages the potential donors to discuss with their family if they have preferences over the organs and tissues which they would like to donate. It also encourages them, however, to choose to maximise the quantity of the organs they would donate, as this could help bridge the gap between organ demand and supply.
- 39 Living organ donation is another option, which all three websites address, providing information and links. The NHSBT and ONT websites, also, provide information on the donation of umbilical cord fetal stem cells and bone marrow.

4.3.4. Subtheme 3.4: Legislature and Default Consent Systems

- 40 All of the websites explained the differences between presumed and informed consent. The NHSBT website presented the legislation in a subsection regarding the UK laws. The NTS website, explained the legal issues in the section of 'Frequently Asked Questions'. The ONT website, in turn, presented not only national but also international legislation.

Table 3 - CROSS COMPARISON OF THE WEBSITES REGARDING DOD IN THEME 3: REGISTRATION OPTIONS.

FEATURES	THEME3: Registration options		
	NHSBT	NTS	ONT
Formal registration	Further links	Further links	Further links
Decision amendment	Further links	Further links	Paragraph
Selective and Live donation	Further links	Further links	Subsection
Donor cards	Further links	Further links	Further links

4.4. THEME 4: Communication with Family Members

- 41 This theme explores the importance of sharing own wishes and decisions about DOD with family and give advice on how to conduct these conversations (**table 4**). One issue in which all three websites strongly emphasise is the importance of sharing views and decisions about organ donation with family, as this informs others about your intentions and decisions, but it also promotes awareness of DOD.
- 42 The NHSBT website has a section ‘Tell your family and friends’ encouraging people to be vocal about their standpoint on DOD. It further explains that there are statistics of family refusal, when they are not aware of their loved ones wish, while the family refusal rate gets smaller when they know the wish of the deceased. The website also shares information on how to conduct a family conversation about DOD. It suggests that any such conversation should follow 3 steps. The first step would be to start with a specific story or news article to trigger the interest. The second step would be to talk about the positive impact of DOD and the third step to share own personal wishes and decisions. Through these steps, the aim is to explain to family that the decision is not ephemeral or hasty but relies on reasoning.
- 43 The NTS website talks about the discussions of the family in regard to the in-hospital protocols. It acknowledges the difficulty of running such discussions within a family, but also suggests that even children 12 years old and above can participate in these conversations and offers some electronic resources which could be helpful.
- 44 The ONT website offers a smaller section of information about family discussions. It makes it very clear, though, that the family’s decision is always respected even though the country has an opt-out system. However, it seems that it is assumed that the family would not have a reason to deny a family member’s wish.

Table 4 - CROSS COMPARISON OF THE WEBSITES REGARDING DOD IN THEME 4: COMMUNICATION WITH FAMILY AND FRIENDS.

FEATURES	Theme 4: Communication with family and friends		
	NHSBT	NTS	ONT
Importance	Further links	Further links	Further links
Advice	Further links	Subsection	Sentence

4.5. THEME 5: Promotional Resources

- 45 The NHSBT website shares educational resources in the 'Get Involved' section, which are appropriate for 11-16 years old students. There are other resources, as well, such as videos and graphics, which visitors are encouraged to share with their friends, so that they can advocate for DOD.
- 46 Similarly, in the NTS website there are lesson plans for primary and secondary education students. It even suggests that guest speakers can be invited in schools to share their expertise on the topic and talk with students (**table 5**).
- 47 The ONT shares downloadable resources, such as calendar, and videos from official advertising agencies about the topic. It is emphasised that the media are a very important link in the advancement of awareness and that there is a constant collaboration with the press to transmit relevant information.
- 48 In the following table, we present in a schematic way the results of the cross-comparison of the three national DOD websites. We summarise the key themes and with the help of bars we show the relative coverage of information for each. The use of one bar indicates that a sentence was dedicated to the subject, two bars shows that a paragraph was dedicated to a theme, three bars indicate that a subsection was used to cover a theme, while four bars show that all of the above conditions were covered with the addition of external links.

Table 5 - CROSS COMPARISON OF THE WEBSITES REGARDING DOD IN THEME 5: PROMOTIONAL RESOURCES.

FEATURES	Theme 5: Promotional resources		
	NHSBT	NTS	ONT
Lesson plans and teaching resources	Further links	Further links	Sentence
Social media: links and lay advocacy resources	Further links	Subsection	Further links
Opportunity for content upload	Further links	Not present	Not present
Patient speaker invitation	Further links	Further links	Not present

5. Discussion

- 49 Our analysis of three national websites revealed five themes which ran across all of them and covered personal values, facts, registration options, communication and promotional resources.

5.1. Wishes, Organ Donation Process and Registration

- 50 Each official website argued in favour of DOD, but focused on different arguments and therefore on different personal values. As emphasised by Hulme et al. (2016), knowledge of patients wishes is strongly associated with obtaining consent for organ transplantation. NHSBT focused on empathy asking people to put themselves in the shoes of the patients, asking them to reflect on their own wishes, encouraging the process of self-reflection in the hope of also communicating wishes to family members and loved ones.
- 51 ONT emphasised solidarity and the utilitarian value of organ donation, while NTS embraced more the matter of personal responsibility to make a decision rather than the aspect of social responsibility. These differences could reflect variations in the three countries regarding the mentality of people and their readiness to support DOD. For example, the high rates of organ donation in Spain could be the reason why ONT briefly addressed the uncertainty on this issue, as the population has demonstrated higher commitment to DOD.
- 52 On the second theme regarding facts on the organ donation process are also differences among the three countries. ONT focuses on the fact that Spain has the highest rate in organ donation and attributes it to the Spanish model, that is the organisation of the system at national and regional level. This is consistent with the findings by Scandroglio et al. (2011) whereby a barrier that was identified hindering consent for donation was the lack of information on effectiveness of transplantation and rates of success as shown on the website. On the contrary, the other two websites emphasise the severity of organ donation shortage by referring to statistics and figures in an effort to raise awareness and turn positive attitude into action. In particular, NHSBT referred to BAME population organ shortage. A high proportion of BAME individuals are the cohort which often require a transplant due to common associated comorbidities leading to kidney failure. Despite this, this group has very low rates of registration. The website explains why it is important for people belonging to these ethnic backgrounds to understand the need to become organ donors, as there is a better match between the donor and the recipient regarding blood and tissue match (Morgan et al., 2016). NHSBT and NTS inform the public about medical criteria and regulations on transplants which apply to all people. On the other hand, ONT explains the evaluation criteria of matching organs and recipients by linking it to the infrastructure and inferring the readiness of the mechanisms to match recipients and organs. A common element in all three websites is the focus on protocols showing that there are strict regulations throughout all stages of the DOD process protecting the rights of all patients whether they are potential donors or not. The level of details, however, differs among the websites. NHSBT and ONT present information but more on the level of facts on definitions of donors and inclusion criteria and technical aspects before a transplant and preparing for an operation. NTS provide detailed explanations regarding the different stages of the process, as they would actually be experienced by recipients and families of donors and recipients, perhaps addressing the most rationalistic audience, who wants to have not only a clear but the full picture of who, how and when is involved in the process. As shown by Truijens and van Exel (2019), by using q-methodology in the Netherlands, one of the barriers to consent and registration was that 'family should decide'. Therefore, covering stages of the

registration and consent process and open communication with family shown in the website is consistent. The lack of information on sub-themes of eligibility criteria and in-hospital protocols from the ONT website can mirror the effect of the presumed consent system, reducing ambiguity regarding eligibility and considering all organs on a case by case basis when they become available.

- 53 The theme of registration options is common to the three websites, as this is the point of translating the positive attitude of a supporter to a registrant. The options of registration are made clear to the users of the websites and although they promote positive attitudes towards organ donation, they explain all registration choices as well as how people can amend their decisions. The difference of the Spanish system, which does not store donor card information in a central registry is explained by ONT, showing the symbolic nature of a donor card, as the country has adopted a presumed consent system, thus clearly depicting the role of family communication. However, the short clarification in paragraphs and subsections makes information more readily accessible than handling external links and emphasises that communication of wishes to family is integral and empowers individuals to adopt this personal responsibility if their opinions of the topic have changed. They also introduce the element of choice and respecting wishes regarding preference of organs they would like to donate. Including links on legislation in a national and international scope on the ONT website is likely to make website visitors put facts and information into perspective and make more informed decisions.

5.2. Variation in resource use

- 54 Chisholm-Burns et al. (2018) discuss the factors influencing the Health-Literacy Model in Transplantation (Heal-T). The model explores three tiers whereby multiple resources are utilised to facilitate access to healthcare, provider-patient interaction and self management. At all three levels patient centered delivery of information is essential. In this study, it was identified that different countries tailor information based on the question and worries people have on organ donation. As family refusals are one of the reasons for not reaching the desired rates of organ donation in the UK and the Netherlands, this topic is emphasised by NHSBT and ONT. NHSBT offers a very structured, step-by-step approach to sharing wishes and decisions to family, encouraging people to link wishes with rational arguments, which would be difficult to be objected to by other family members. NTS also suggests ways of initiating conversations within families to ensure that wishes are and puts emphasis on the role of family at the time of donation and conversations with health professionals. Although ONT explains the role of family consent, it emphasises mainly that the family expresses the wish of the potential donor. It projects the importance of family decisions and the duty of the health professionals to respect it. We could assume that it relies more on the sense of families not having any arguments against organ donation rather than the power of legislation to persuade the organ donation. ONT also seems to take for granted that families will give consent even if no formal family discussions have taken place, probably because not referring an objection could be considered as an endorsement.
- 55 The theme of promotional resources also shows slight differences among the websites. NHSBT and NTS share a variety of resources for schools and engagement of the

community to the cause of organ donation. As described in NHSBT these resources can be used by teachers in the Personal, Social Health Education subject and encourage students to reflect on this topic and engage in a conversation with their family by forming lesson plans and inviting experts to clarify queries about the subject. This has been integrated and proved effective in the Netherlands as shown by Reubsaet et al. (2005) which promoted pupils to have positive registration intentions and negative views on the subject. ONT emphasises more strongly its links with the media, perhaps considering them as the main channel of shaping the public's attitudes. This is particularly important in the social media age, as messages can be readily shared, endorsed by influencers, public figures and platforms allow opinions to be shared by anybody readily.

5.3. Ways Forward

- 56 The websites provide information at two levels. At the individual level the websites aim at enhancing the knowledgeability of the users, highlighting social aspects, such as organ shortage and practical aspects, such as hospital protocols and registration options. Health Literacy in these two domains could be further facilitated by discussing such topics in Personal and Social Health Education in secondary school, college and university. This could be particularly effective in Spain, as it showed the lowest levels of teaching resource availability on the website. At a community level, priorities are given to communication of wishes and decisions and promotion of advocacy. In the Netherlands lower levels of social media links and content upload were noted. Audio-visual means, testimonials and frequently asked questions provide short and concise information which do not necessarily focus only on facts but also on personal experiences; which is included in the HeaL-T model affecting self-management. These sources should be the priority for spreading awareness within the population and initiating discussion of feelings and wishes towards DOD with close friends and family. The themes extracted from these websites was the basis of a DOD-Health Literacy questionnaire which was distributed to Spain, UK and the Netherlands to construct support vs registrant profile to better inform Public Health Campaigns on organ donation (Theodosopoulou, 2020).

5.4 Limitations

- 57 The websites are flexible resources, as they can be regularly updated in regard to content and form. The review of the websites reflects the time of the analysis. On 20 May 2020, the legislation regarding organ donation in England changed, adopting the opt-out system. A new review of the current NHSBT website would be of merit.

6. Conclusions

- 58 The worldwide organ shortage problem is a clear indicator of the urgent need of health literacy among the lay population about organ donation. Health literacy principles and initiatives should be undertaken to ensure that the facts are clearly presented, the process of DOD is explained and the need to become lay advocates communicating own wishes and decisions is highlighted.

- 59 The Internet resources become more and more prominent as more people use it as a place for accessing health information. Reviewing and comparing the information about organ donation in the official websites about organ donation in the UK, the Netherlands and Spain gave a panoramic view of the content of information that people in these three countries have access to. Similarities among them show that information is gathered around personal values, facts, registration options, communication with family and promotional resources. Differences in the emphasis given on aspects of organ donation portray different needs of mobilisation of the population and possibly different societal values. On an individual and community level, early education on the topic tailored to specific countries is essential, whilst on a population basis, large scale media campaigns with personal patient stories and experiences should be advertised and advocated.
- 60 Health literacy campaigns on DOD should acknowledge both the need for raising awareness of needs, processes, values and wishes and the need to engage in action by registering own wish, communicating it with family members and advocacy.
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ABSTRACTS

Making informed decisions such as organ donation requires access to accurate, readily available and reliable information. One of the most easily accessible resources are the official national websites of countries around the topic of Deceased organ Donation (DOD). The content of the official organ donation websites in the UK (NHSBT), the Netherlands (ONT) and Spain (NTS) were analysed. This is a step towards finding the parameters of a health literacy agenda on organ donation and transplantation. Cross-comparative content analysis was employed and subsequently thematic analysis was used to locate themes and sub-themes in the sections of these websites and coverage of themes was assessed. The analysis was performed using Atlas.ti software in 2014-2016. The information provided in these websites were categorised in five themes consisting of Theme 1: Personal Values for Organ Donation, Theme 2: Facts on the Organ Donation Process, Theme 3: Registration Options, Theme 4: Communicating with Family Members and Theme 5: Promotional resources. Within themes 2 and 3, further sub themes were identified to explore the topic more fully. The information in the websites provides an overview of the main areas of organ donation in which the public is informed in different countries and highlights that changes need to be implemented in an individual, community and population level.

INDEX

Keywords: health literacy, organ donation, transplants, national websites, raising awareness

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