INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

AGEING WITH SPINA BIFIDA AND HYDROCEPHALUS

A DESCRIPTIVE ANALYSIS

Co-funded by the Rights, Equality and
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Union

INDEX


CIRCLE K

DEFINITIONS & ACRONYMS

DEFINITIONS

What is the International Federation for Spina Bifida and Hydrocephalus?

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with spina bifida and hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional organisation of persons with disabilities with global coverage, democratic structure and transparent and accountable processes.

The mission of the International Federation for Spina Bifida and Hydrocephalus is:

- to improve the quality of life of people with spina bifida and hydrocephalus and their families
- to reduce the incidence of neural tube defects and hydrocephalus by primary prevention;

by raising awareness, and through political advocacy, research, community building and human rights education.

What is Spina Bifida?

Spina bifida is a congenital condition, which means that it has developed during pregnancy and is present at birth. The words spina bifida literally mean "split spine", as during the first 4 weeks of pregnancy and onwards, the neural tube and spine will not have developed correctly. The neural tube is the part of the embryo from which the brain and spinal cord are formed. A disruption of this process can occur anywhere along the spine.[1]

What is Hydrocephalus?

Hydrocephalus is one of the most commonly associated conditions with spina bifida, as is a condition called Chiari II malformation, or hindbrain herniation. Hydrocephalus is also called "water on the brain". This "water" is actually cerebral spinal fluid (CSF), which is produced by the brain, and surrounds it, for instance to protect it against trauma. Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed into the bloodstream. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.[1]

What are Neural Tube Defects?

Neural Tube Defects (NTDs) are a group of congenital conditions that occur when the neural tube (which later goes on to form a baby's brain and spine) fails to close completely, leaving a split or gap in the spine. Spina bifida is the most common NTD.[2]

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[1] https://www.ifglobal.org/spina-bifida-and-hydrocephalus/

[2] https://www.ifglobal.org/wp-content/uploads/2019/02/Neural-Tube-Defects-final-1.pdf

ACRONYMS

IF: International Federation for Spina Bifida and Hydrocephalus

SBH: Spina Bifida and Hydrocephalus

WHO: World Health Organization

NTDs: Neural Tube Defects

CSF: cerebral spinal fluid

INTRODUCTION

Spina bifida and hydrocephalus (SBH) are complex health conditions leading in many cases to disabilities involving cognition, behaviour, and neurological dysfunctions. These are the most common NTDs, which affect over a quarter of a million annual birth outcomes worldwide[1]. However, rapid developments in medical science, advancement of technology and improvement in healthcare practices have seen a significant increase in the life expectancy of babies born today with these conditions.

Data from the last three decades[2] suggest that more than 75% of newborns will reach adulthood and it is predicted that the numbers of older people with SBH will rise dramatically over the next few decades. Yet, whilst the knowledge base concerning neonatal and paediatric care is growing, there is little known about the impact living with SBH has on transitioning to old age. There is a need to explore and expand our knowledge and gain insights into current health and wellbeing status of older people with SBH. We need to understand the challenges they face, their way of developing resilience and coping mechanisms and the impact ageing has on their occupation and independence.

The International Federation for Spina Bifid and Hydrocephalus (IF), the worldwide umbrella organisation for SBH organisations, already published a position paper on “Healthy Ageing” in 2012[3]. At the time and based on evidence collected from a range of stakeholders, including an online survey (n=52), IF called for a coordinated action to support what was described as an “urgent need” for older people with SBH to receive the services they require and deserve.

Eight years later and as we embark on what the World Health Organization (WHO) coins a Decade of Healthy Ageing (2020-2030)[4] , it is important to evaluate progress to date and improve our understanding of the lived experience of older persons with SBH. To this end, in the summer of 2019 IF commissioned a follow-on and Europe-wide study where data was collected using an online survey. An earlier Norwegian study[5] , which was championed by a board member who was involved in the original work, informed initial developments.

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[1] Blencowe, H., Kancherla, V., Moorthie, S., Darlison, M. W., & Modell, B. (2018). Estimates of global and regional prevalence of neural tube defects for 2015: a systematic analysis. Annals of the New York Academy of Sciences, 1414(1), 31–46.

[2] Bowman RM, McLone DG, Grant JA, Tomita T, Ito JA. Spina bifida outcome: a 25-year prospective. Pediatr Neurosurg. 2001;34(3):114-120

[3] https://www.ifglobal.org/publications/if-position-paper-on-healthy-ageing/

[4] https://www.who.int/ageing/decade-of-healthy-ageing

[5] Lidal IB, Lundberg Larsen K, Hoff M. 50 Years and older - born with spina bifida: participation, health issues and physical function. Disabil Rehabil. 2019;1-10.

The data collection tool, co-created with service users, was translated into 12 languages and distributed to individuals through their national organisations and social media channels.

The quantitative numeric data, captured from all participants (n=650) who completed part of or all the 39 questions, were analysed using descriptive statistics aided by IBM SPSS software. The free text comments were analysed using qualitative thematic analysis[1] aided by QSR NVivo software[2] . The use of mixed methods to analyse online surveys adds a "wide-angle lens" to the subject[3] and a unique gaze with which to review the current 'state of play' across Europe.

However, while we were seeking to capture and understand the raw qualitative data, it must be stressed that there is no one true lived experience that we unearthed. In fact, the survey responses describe 650 different lived experiences, each as valid and as real as the others. It is also important to note that whilst it is possible to retain a sense of objectivity when analysing quantitative data (numbers), it is difficult – some would argue impossible – to do so when dealing with subjective narratives. This is important because in identifying and describing themes, the data is not only being reported it is being subjected to active interpretation.

For this reason, we set to clearly articulate the methodology we used and offer transparency about the methods, assumptions and (potentially unconscious) bias involved in the analysis process. In this way, the reader is made aware of the potential bias of the researchers and can take it into account when considering the rigour of the analysis and the robustness of the conclusions drawn from it. Highlighting the limitations of the study should also enable the reader to consider the potential impact these have on the applicability of the specific recommendations offered in this report.

We suggest that a further qualitative study is carried out, which adopts a more in-depth approach to data collection, to affirm overall findings presented here. We believe this may help service users to plan appropriate care pathways in collaboration with clinicians, as they transition to old age. We also hope that results impact and influence policy makers, across Europe, to fund more and better facilities to help and support those ageing with SBH.

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[1] Guest, Greg, Kathleen M MacQueen and Emily E Narney. 2014. "Introduction to Applied Thematic Analysis." In Applied Thematic Analysis, 3-20. Thousand Oaks: SAGE.

[2] https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

[3] Terry, Gareth, and Virginia Braun. 2017. "Short but Often Sweet: The Surprising Potential of Qualitative Survey Methods." In Collecting Qualitative Data: A Practical Guide to Textual, Media and Virtual Techniques, edited by Virginia Braun, Victoria Clarke and Debra Gray, 15-44. Cambridge: Cambridge University Press.

METHODOLOGY

Following an IF workshop in Madrid, where the project was conceived, a small pan-European steering group, supported by IF staff, led the development and planned cascade of the agreed data collection tool. To reach out to a wider population we used a commercial online portal (www.surveymonkey.com) and the English version of the survey went 'live' on the 17th of June 2019. A social media recruitment campaign and 'nudging' followed, and all IF European Members were informed and encouraged to participate in the study from the very outset. To increase accessibility, the survey was also translated to 11 other European languages and shared widely using the established IF website, newsletters and virtual social media networks. The portal remained open for over 3 months and closed on September 30th and the software aggregated instant results. Participants came from 26 countries across Europe and as can be seen in **Table 1 (Appendices)**, the largest group of participants originated from Germany (15.1%) and the UK (14%), followed by the Netherlands (11.4%) and France (10.6%).

Structure

The questionnaire was divided into several segments and used the United Nations Convention on the Rights of Persons with Disabilities[1] as a guiding framework. Sections included: "General information", "General overview", "Right to appropriate housing of your choice", "Right to personal mobility", "Right to employment", "Right to access, to support and to social protection", "Right to participate in the life of the society", "Right to health" and "Additional information" .

Some questions offered additional free text input and the online survey portal enabled participants to add narrative in their mother tongue. This qualitative data had to be translated back into English and uploaded onto the specialist software used for thematic analysis. The coding of text was done through collaboration of 2 researchers who were able to confer themes and relate findings to a transition theoretical framework that further aided analysis. The chosen 6 phase approach to analysing data[2] , entail an immersion in the data through repeated close reading of text to identify recurrent patterns and themes. Once a theme (a node in NVivo; the terms are used interchangeably here) has been identified, the narrative is 'coded' to it and this cycle continues whilst more data is explored.

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[1] https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

[2] Braun, Virginia & Clarke, Victoria. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology. 3. 77-101

Subjects

Each theme can be thought of as a flipchart to which 'post-its' with relevant text are stuck. This allowed the text coded to each theme to be easily reviewed and assessed on whether they continued to 'make sense' in the light of the growing narrative content. It is important to note that this is an iterative process, with new themes emerging along the exploration journey, as more data is added. It should also be noted that some nuance embedded in context may have been lost in the translation process and subsequent analysis of the data.

As expected, specific survey questions attracted comments relevant to the issue raised by that topic. For example, the question on housing would be more likely to elicit narrative relevant to the way the participants experience their living space. However, as more text was examined the 'suitability' of the 'home' was added as an emerging theme. Linking nodes conceptually, enabled further relevant text to be coded, including comments made in relation to other topics or questions. Some themes contained sub or child branches that were linked to a 'parent' node. For example, a 'Resilience' theme had contributing nodes that emerged during the initial coding, when the raw data was explored. Considering the newly ordered narrative and linking similar nodes, helped to 'discover' an overarching concept of resilience that in turn added an additional layer to our understanding of the narrative.

In addition to the cyclical process that guided our approach to narrative analysis, country specific data was also grouped as separate 'cases'. This allowed us to exploit the computational capabilities of the NVivo software to cross-tabulate results, enabling further insights to emerge. For example, it was possible to look at the number of items for each theme that came from the different countries surveyed. We also used data visualisation to gain further understanding of narrative in a form of 'word clouds'. This entails calculating the frequency of each word used and representing this visually, with the most frequent words appearing in larger font. A word cloud gives a quick visual picture of the material, facilitating contextual analysis of how each word is used[1] . In the following sections of the report narratives complement the use of word clouds to offer a clearer picture.

Preliminary results

The preliminary results were first presented and discussed in October 2019, at an IF European workshop held in Ghent, shortly after the survey closed. Attendees included people with the conditions, members of their families, healthcare professionals as well as carers and personal assistants. Sharing some results and reflecting on feedback enabled the steering group to hone the analytical gaze and consider the findings in the context of the wider stakeholder community. The involvement of a steering group was a critical factor in co-creating the final report to ensure findings relate to and support the overall aim of involving people with SBH in the work of IF and representing their views. Further analysis was presented in a follow up workshop in July 2020, at an event held online.

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[1] https://researchportal.bath.ac.uk/en/publications/using-word-clouds-in-teaching-and-learning

DEMOGRAPHICS

The questionnaire segmented the population to four age groups: 35-44, 45-54, 55-64 and over 65 years of age. As can be seen in **Figure 1**, the majority of participants (n=328, 50.46%) were those with an age range of 35-44 years. The inclusion of this age range in a study that focused on ageing may seem surprising. However, the steering group took the approach that even though in most European countries, 60 or 65 is the age of eligibility for retirement and old-age social programs, our target population may experience accelerated ageing. In fact, only 24 participants were over the age of 65 and with those over 55-year-old the combined categories constituted but a fifth of the total sample (17.69%). This specific spread of ages and the impact it has on the overall results will be further explored in the discussion chapter of this report.

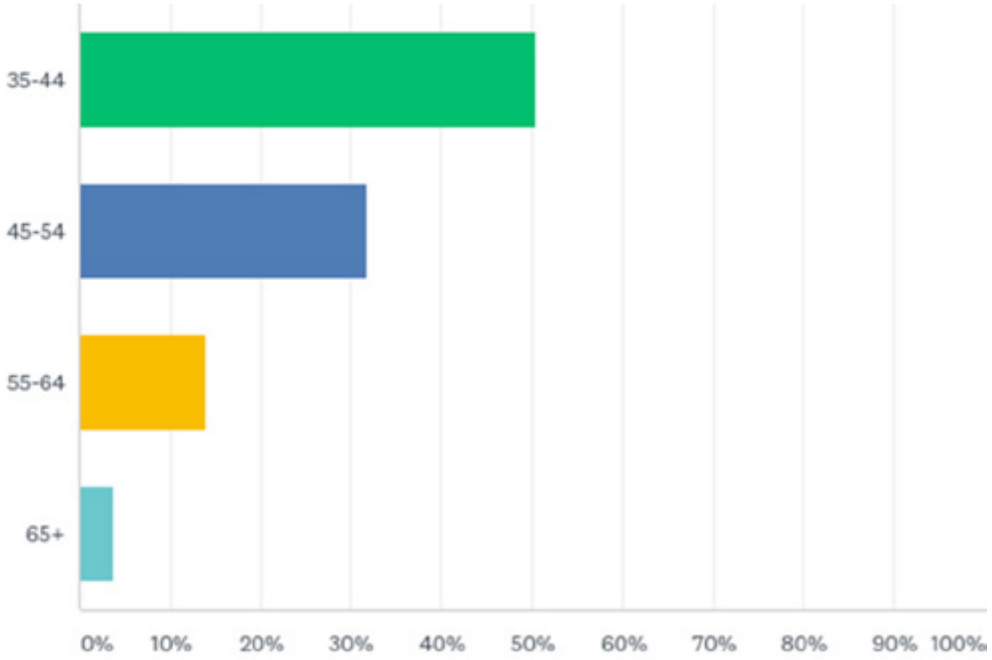


Figure 1 Age distribution

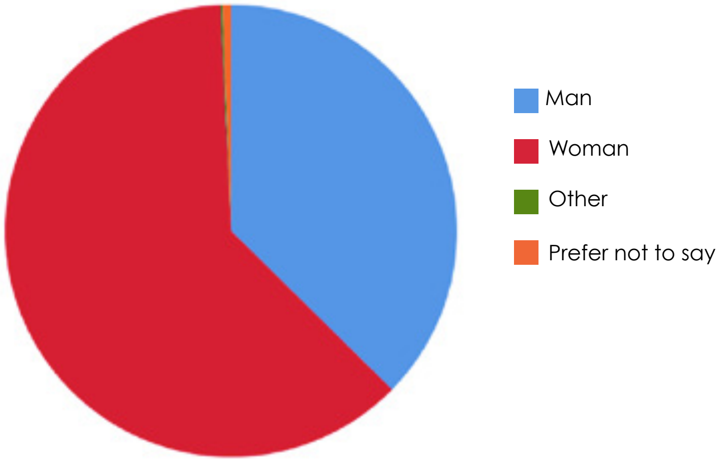
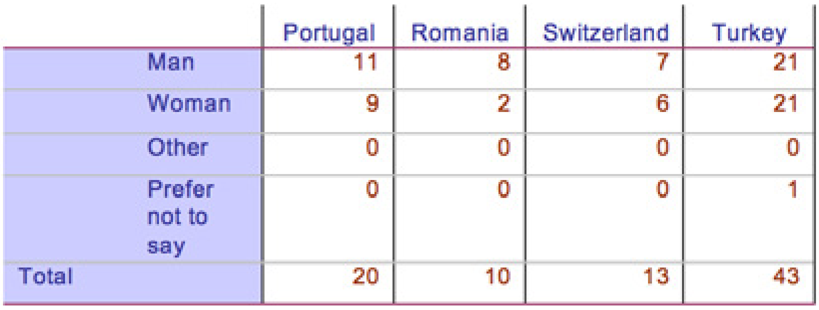


Figure 2 Gender distribution

Figure 2 highlights the overall gender distribution, which was observed amongst most European countries except for Portugal, Romania, Switzerland and Turkey **(Table 2)**.

Table 2 Gender distribution



	Portugal	Romania	Switzerland	Turkey
Man	11	8	7	21
Woman	9	2	6	21
Other	0	0	0	0
Prefer not to say	0	0	0	1
Total	20	10	13	43

The education attainment of participants is depicted in **Figure 3**, showing that the great majority of participants completed high school education with a large number progressing further and graduating from University too.

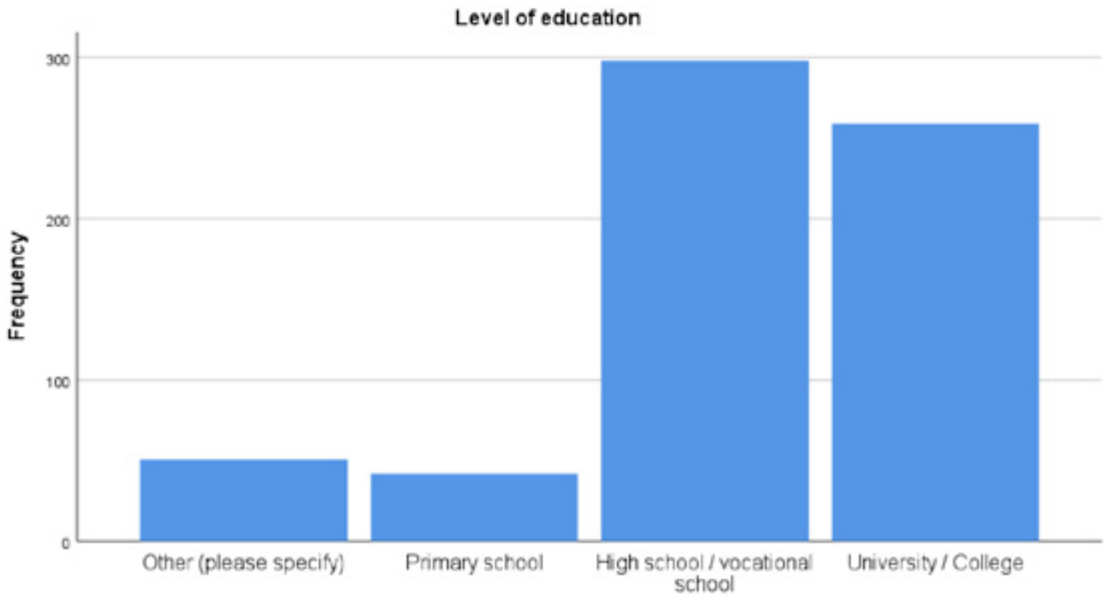


Figure 3: Level of education

Just under half (48%) of all participants indicated they have "Both Spina Bifida and Hydrocephalus" with 44% stating they have "Spina Bifida Only" and 8% aligning themselves to the "Hydrocephalus Only" category. The great majority of people who responded to the survey were a member of a national association (64%) but the study also reached a significant proportion of people who are not members (36%, n=233). It may be that the use of social media enabled the cascade of information beyond the boundaries of a population known to local organisations.

The majority (54%) of participants were in full or part-time employment with only 16% stating they are retired or identified themselves as old-age pensioner. When asked if they have looked for information related to ageing with spina bifida or hydrocephalus 60% (n=295) indicated that they were not actively seeking such information, yet.

GENERAL OVERVIEW

The survey asked participants to indicate their overall ageing status, at an early point in the survey, to capture responses from those who may not complete the long survey to the end. Participants were asked to consider different facets of ageing by responding to a question about their 'health and wellbeing', 'ability to work', 'housing', 'mobility', 'relationships / sexuality' and 'social life'.

As can be noted in **Figure 4 (Appendices)**, the great majority of participants (78%, n=469) indicated that they are experiencing a deterioration of their health and wellbeing with 32% seeing a significant deterioration. However, as shown in **Table 3**, there is a clear correlation between deterioration of health and wellbeing and advancing age. A far larger proportion of those who are over the age of 65 report significant deterioration (71%) compared with those in the 35-44 age bracket (18%).

Table 3: Correlation of aae and deterioration of health

		35-44	45-54	55-64	65+	
Your health and well-being	Significant deterioration	(18%) 53	(29%) 85	(46%) 38	(71%)17	193
	Slight deterioration	(51%) 152	(29%) 86	(37%)31	(29%) 7	276
	No changes	(26%) 76	(8%) 25	(10%) 8	0	109
	Slight improvement	8	3	2	0	13
	Significant improvement	9	1	4	0	14
Total		298	200	83	24	605

The ability to work was another specific facet that participants considered and the majority (36% n= 214) indicated that they observe no changes due to ageing. Again, the correlation to age is clear and as seen in **Table 4**, advancing age has a negative effect on the ability to work. Whilst 17% of those younger participants feel their ability to work was significantly deteriorated due to ageing, the percentage is more than double (39%) amongst the 45-54 age group and tripled to 51% by those in the 55-64 age bracket.

Table 4: Ability to work and age

		35-44	45-54	55-64	65+	
Your ability to work	Significant deterioration	(17%) 49	(39%) 78	(51%) 43	(48%) 11	181
	Slight deterioration	(31%) 93	(31%) 61	(24%) 20	(35%) 8	182
	No changes	(46%) 137	(28%) 56	(20%) 17	(17%)	214
	Slight improvement	9	2	2	0	13
	Significant improvement	8	1	2	0	11
Total		296	198	84	23	601

The reported impact of ageing on housing was less significant but had a similar trend to the impact noted with the ‘ability to work’ category: the majority (54%, n=324) reported no change. Yet, as can be seen in **Table 5**, the older the participant gets, the harder the housing situation becomes. Whilst only 8% of the younger participants note a significant deterioration, this proportion doubles for the 45-64 age group and quadruple for those over the age of 65.

Table 5 Housing situation and age

		35-44	45-54	55-64	65+	
Your housing situation	Significant deterioration	(8%) 25	(16%) 32	(17%) 14	(33%) 8	79
	Slight deterioration	(21%) 61	(24%) 47	(26%) 22	(42%) 10	140
	No changes	(60%) 178	(52%) 102	(46%) 39	21%) 5	324
	Slight improvement	11	7	3	0	21
	Significant improvement	21	8	6	1	36
Total		296	196	84	24	600

When asked about mobility and the ageing process a significant number (72% n=444) of participants noted a deterioration or a severe deterioration in their condition, as shown in **Figure 5 (Appendices**). Again, there was an apparent correlation between age and deterioration of mobility noted in **Table 6**: Only 20% amongst the younger participants attributed ageing to a significant deterioration, while 75% of the over 65 years old noted a significant deterioration.

Table 6 Mobility and age cross tabulation

		35-44	45-54	55-64	65+	
Your mobility	Significant deterioration	(20%) 60	(37%) 74	(48%) 40	(75%) 18	192
	Slight deterioration	(44%) 130	(43%) 86	(36%) 30	(25%) 6	252
	No changes	(29%) 86	(16%) 31	(13%) 11	0	128
	Slight improvement	12	4	0	0	16
	Significant improvement	9	4	3	0	16
Total		297	199	84	24	604

Including a question about relationship and sex was important for steering group members but as can be seen in **Figure 6 (Appendices)**, the majority of participants (50.2%) reported no change to this aspect of their lives. Looking at the data in **Table 7 (Appendices)** and the age segmentation, it is clear that age is a key factor to self-reported deterioration. Finally, the general overview section asked about ‘social life’, which is an important element in addressing some of the challenges all people face as they age. Results show that most (48%) report no change to social life but age is a contributing factor in self-reported deterioration, as can be seen in **Table 8 (Appendices).** Quantitative and qualitative analysis of data is further reported in the following sections.

HOUSING & HOME SUITABILITY

As noted previously, participants were asked to complete an overview question at the very outset of the survey and then were given an opportunity to complete further questions. This additional cluster of questions was given the heading: “Right to appropriate housing of your choice”. Data shows that the great majority of participants (92%) are living in a house or apartment and many of them live alone (n=230, 39%). Over a third of those who answered this question (n=590) live with a spouse or cohabitant and just over 8% were living in a different dwelling and ticked the ‘other’ option. Only 4% of participants live with children (n=23).

Just over half (53%) of participants feel their home is suitable for their perceived age related needs and as can be seen in **Table 9** this was across all ages.

Table 9 Age and home suitability

		Is your home suitable for your perceived ageing-related needs?			
		Yes	No	Partly	Total
What is your age? Please check the appropriate box.	35-44	149	74	63	286
	45-54	105	38	54	197
	55-64	42	19	21	82
	65+	14	2	7	23
Total		310	133	145	588

Interestingly, there appears to be a correlation between age and suitability of the home, whereby older participants found their home more suitable than their younger counterparts. However, the perception across Europe is somewhat different as can be seen in **Table 10.** The great majority of participants from Portugal (80%) Holland (79%) and Norway (71%) identified their home as suitable but that was not a uniformed picture across all countries. Home suitability for participants in Belgium (29%) and Spain (24%) was poor and France (37%), Germany (41%) and Sweden (41%) were below the 50% mark too.

When asked whether they expect to remain in their current home in the next 10 years most participants said ‘Yes’ (55%), but a quarter responded with ‘I don’t know’. When age was factored in the analysis this was found to be the case across all age groups as can be seen in **Table 11**.

Table 10 Home suitability across Europe

		Is your home suitable for your perceived ageing-related needs?			
		Yes	No	Partly	Total
Which European country do you live in?	Austria	4	0	2	6
	Belgium	(29%) 7	5	12	24
	Czech Republic	1	0	0	1
	Denmark	3	1	1	5
	Finland	5	2	0	7
	France	(37%) 24	25	16	65
	Germany	(41%) 37	21	32	90
	Greece	0	2	0	2
	Hungary	0	0	1	1
	Ireland	(62%) 24	9	6	39
	Italy	(67%) 22	4	7	33
	Lithuania	1	0	0	1
	Luxembourg	1	0	0	1
	Malta	1	1	1	3
	Netherlands	(79%) 54	3	11	68
	Norway	(71%) 10	1	3	14
	Poland	0	1	0	1
	Portugal	(80%) 16	1	3	20
	Romania	3	2	2	7
	Slovakia	0	0	2	2
	Spain	(24%) 4	7	6	17
	Sweden	(41%) 8	17	9	44
	Switzerland	(62%) 8	4	1	13
	Turkey	(50% 18	8	10	36
	United Kingdom	(56%) 49	19	20	88
Total		310	133	145	588

Table 11 Future suitability of home per age

		Do you expect to remain in your current home in the next 10 years?			
		Yes	No	I don't know	
What is your age? Please check the appropriate box.	35-44	150	65	72	287
	45-54	112	35	50	197
	55-64	47	13	22	82
	65+	13	3	6	22
Total		322	116	150	588

The systematic scrutiny of narrative, as part of the qualitative analysis, commenced with the UK and Irish responses before content from other countries was added. This incremental addition of data allowed the identification of a unique distinction between the UK and Irish responses, through a recurrent reference to a specific word: 'bungalow'. It appears to capture the housing solution people in those countries aspire to have: a single-story detached dwelling. However, as more data from other European countries was added, the use of the word became less frequent resulting in less prominence within the word cloud.

Text relating to housing was categorised into two nodes: Home Suitability – things that made a home suitable to live in – and Home UNsuitability – things that made a home more difficult to live in. In the word clouds that were constructed, using content of these nodes, the words 'apartment', 'wheelchair' and 'accessible' had a larger font, suggesting they are often mentioned by participants. However, the context distinguishes suitable housing as accessible – whereas the lack of accessibility makes the home UNsuitable, see **Figure 7 (Appendices)**.

Analysis suggests that people remained in an UNsuitable home for two main reasons – money and/or lack of a suitable alternative:

> "I'm forced to stay in that inaccessible home because I have not enough money to go elsewhere and it is impossible to have access to an accessible home because they are too expensive and not in my neighbourhood."

Interestingly, using a 'heat map' (the greater the number of mentions, the more intense the colour) shows the number of comments coded to 'home suitability' and to 'home UNsuitability' per country, see **Figure 8 (Appendices)**. The map clearly shows that in The Netherlands, Sweden and Switzerland, more respondents were content with their housing situation, which may relate to financial aid and availability of adapted housing in these regions.

It is important to stress that the issue of accessibility was not relating solely to entry level access and wide door frames for wheelchair users. Many people commented on the increased actual or perceived future challenge posed by steps, internal and external, and the lack of a lift. Overall, analysing the comments about housing brought a sense of "life being made more difficult" by these physical obstacles and aligned to findings that relate to coding of Pain and Tiredness.

MOBILITY, ASSISTIVE DEVICES, AND GOVERNMENTAL SUPPORT

As identified previously, mobility difficulties were a challenge that affected the great majority of participants. This additional cluster of questions was presented with the heading of "Right to personal mobility". The great majority of people (77% n=436) use aid to move in or outside the home environment. Specifically, Wheelchairs (72%), Walking aids (42%) and Orthopaedic aids (27%) were mentioned by participants. As can be seen in **Table 12**, people in Norway have the highest 'usage aid ratio' whereas Turkey has the lowest ratio between users and aids. It is important to note that as they progressed towards the halfway stage, fewer people continued with completing all the questions with only 567 of the original 650 respondents completing question '12' on assistive devices, a 13% dropout.

Table 12 Assistive devise use per country

Do you use assistive devices to move around, either inside your home or outside?

		Yes	No	Total	Percentage of users
Which European country do you live in?	Belgium	20	4	24	83%
	France	41	21	62	66%
	Germany	68	18	86	79%
	Ireland	32	5	37	86%
	Italy	20	11	31	65%
	Netherlands	58	10	68	85%
	Norway	13	1	14	93%
	Portugal	12	8	20	60%
	Spain	11	4	15	73%
	Sweden	36	6	42	86%
	Switzerland	10	3	13	77%
	Turkey	15	17	32	47%
	United Kingdom	72	14	86	84%

Participants were asked whether and how their personal mobility needs have changed in the last five years. As can be seen in **Figure 9 (Appendices)**, a large proportion (35%) of participants stated that their mobility needs have not changed. Just under a quarter (24%) noted that they rely more on assistive devices when they go outside but affirmed that their needs inside the home have not changed. Just under a third (30%) noted that rely more on assistive devices both inside and outside and a fifth (21%) stated they now require new assistive devices that they did not need previously. A similar proportion (21%) rely more on personal assistance.

In the follow up question, participants were also asked if they receive adequate input from the government (or other agencies) to support changed personal mobility needs. Whilst this question was relevant only to those who noted change in the last 5 years, we were unable to construct algorithmic navigation within the survey.

As such, all participants were asked to answer, with the majority of participants (56%) suggesting that government support for mobility issues is inadequate (**Figure 10**). As can be seen in **Table 13** only a very few countries were noted as offering adequate support including Italy, Netherlands, Norway, Sweden and Switzerland.

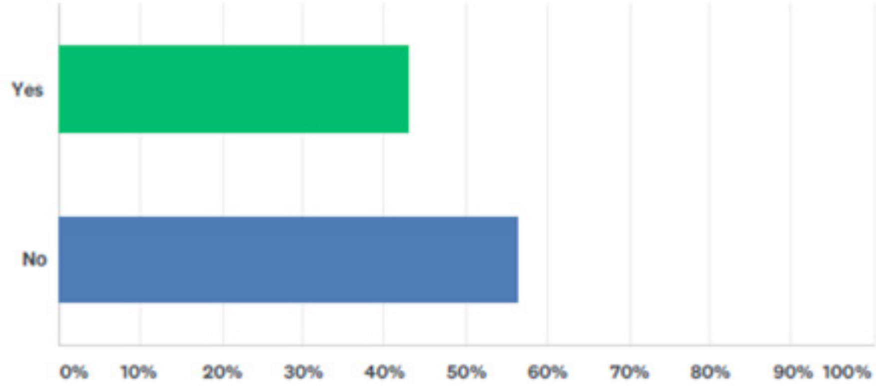


Figure 10 Governmental support to mobility issues

Table 13 Government support to address mobility issues per country

		Yes %	No %	
Which European country do you live in?	Austria	67	33	
	Belgium	50	50	N=24
	Czech Republic	0	100	
	Denmark	25	75	
	Finland	57	43	
	France	37	63	N=62
	Germany	46	54	N=80
	Greece	0	100	
	Hungary	0	100	
	Ireland	36	64	N=36
	Italy	53	47	N=30
	Lithuania	0	100	
	Luxembourg	100	0	
	Malta	33	67	
	Netherlands	56	44	N=68
	Norway	62	38	N=13
	Portugal	30	70	N=20
	Romania	14	86	
	Slovakia	0	100	
	Spain	43	57	N=14
	Sweden	52	48	N=42
	Switzerland	54	46	N=13
	Turkey	17	83	N=29
	United Kingdom	39	61	N=85

EMPLOYMENT

As noted previously, over half of participants were employed (54%) with more than a quarter (28%) holding full-time jobs. As can be seen in **Figure 11**, a fifth (22%) described themselves as unemployed and 16% (n=89) stating they are retired.

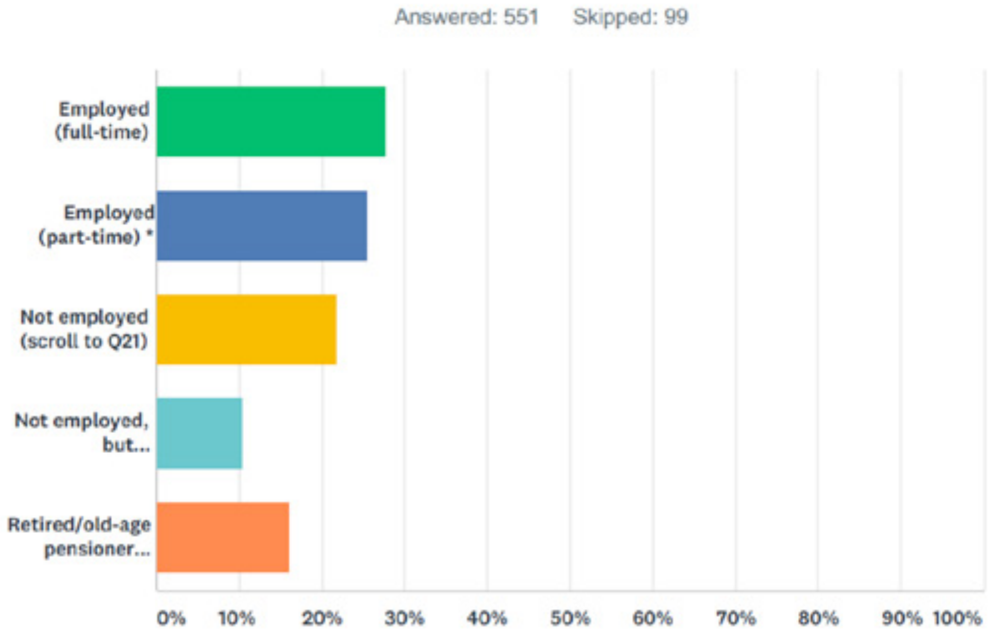


Figure 11 Employment

When employed people were asked if they work less now than 5 years previously, for the great majority (73% n=267) the answer was no – they continued to work at the same level as in the previous years and 54% (n=196) of them expect to work at the same level in the next 5 years too. However, amongst those who reduced the level of employment (27% n=97), in the majority of cases this was due to their SBH (61%). Again, these results have a direct correlation to age, with older participants being more affected by the condition leading to reduced level of employment.

The qualitative analysis suggests that for some respondents, employment (and related to that, education) was an arena where the challenges posed by SBH could be overcome. Moreover, for a few the fact that they were employed and 'useful' was a source of pride and even affirmation. However, for many others, finding employment was difficult and this was often directly related to the attitude of employers and accessibility of the workplace:

> "Once you mention you have a disability they just don't want to know"
>
> "Up hill battle to convince people to see past what I can't do to what I can"
>
> "From the moment you enter, you are judged on your difficulty with walking. People think that you have a mental disability as well then"

> “Was quite difficult due to inaccessible buildings and lack of wheelchair accessible bathrooms”

There were several comments to the effect that the public sector was better than the private sector – perhaps because the public sector is more responsive to regulations regarding accessibility and equal opportunities.

STATE AID & SUPPORT

Participants were asked whether they have access to statutory formal support (e.g. social worker, home nurse, personal assistance) or informal support, including help offered by family or friends. A large number (31% n=157) indicated they have no support at all, but that factor does not impinge their independence at present. For half of those who responded, their support needs are fully covered by formal and/or informal agents or partly covered (32%). As can be seen in **Table 14**, the Netherlands stands out as a beacon of support, with Turkey being the place with the highest proportion of participants whose needs are not being met.

Table 14 Support needs per country

		Are your support needs covered?			Total
		Yes	No	Partly	
Which European country do you live in?	Austria	3	0	2	5
	Belgium	8	5	9	22
	Czech Republic	1	0	0	1
	Denmark	1	1	3	5
	Finland	5	0	0	5
	France	20	13	18	51
	Germany	37	13	28	78
	Hungary	0	0	1	1
	Ireland	17	4	12	33
	Italy	11	3	11	25
	Lithuania	1	0	0	1
	Luxembourg	0	0	1	1
	Malta	1	0	1	2
	Netherlands	45	4	15	64
	Norway	9	2	1	12
	Portugal	13	3	3	19
	Romania	3	5	0	8
	Slovakia	2	0	0	2
	Spain	6	4	2	12
	Sweden	20	9	11	40
	Switzerland	6	0	3	9
	Turkey	5	9	9	23
	United Kingdom	34	17	28	79
Total		248	92	158	498

The survey also asked about receipt of financial entitlements/state benefits (such as housing, disability, unemployment, or tax benefits), in-kind support (such as social housing, social services, personal assistant, or other) and health insurance. About a fifth (17%) of all participants were not in receipt of aid, benefits or support and the correlation to age suggests that it is those who are younger, in employment and in relatively good health that are not in receipt of financial aid or in-kind support.

When asked whether in the last five years they have experienced a reduction in eligibility to entitlements only 16% agreed, with the great majority (61%) offering a resounding – No. Participants were also asked to think about the future and consider whether they expect a reduction in the eligibility to entitlements due to ageing with SBH in the next five years. Nineteen percent said yes, with many (38%) opting to tick the 'I'm not sure' option.

The analysis of narrative concerned with the level of support received suggests that there were a few with very positive experience of dedicated assistance:

"Occupational health services were amazing at getting me a stair lift so I could be independent in whole house"

However, many more expressed frustrations at complex bureaucracy and support denied either due to assessment of needs or entitlement for financial aid:

> "I don't have any help, despite several applications, although I would really need it"
>
> "Declined - the need is not there. I'm very angry!"
>
> "Once you can work they don't care"

There was a consistent thread, across all countries, that success in obtaining help often depended upon inside help from within the system – for example, occupational health as cited above. This added to the impression of people grappling with an outdated or opaque system, resulting in feelings of unfairness. Yet, there was acknowledgement, by some, that basic needs were being met:

> "From a personal and nursing point of view, I can't complain"
>
> "I have a carer for showering in a mornings and a carer for helping get ready for bed in the evenings and a carer once a week for cleaning"

Nevertheless, needs for things that make life easier – help with housework, gardening etc. - were left unfulfilled:

> "Require domestic support but have no access to this as it has low priority with statutory services"
>
> "I urgently need a cleaner. I don't currently earn enough to be able to afford one and I'm too fit for a nursing level"
>
> "I don't have any help and I don't know where to turn to get some. I would really need help for housekeeping, garden, etc. I am too tired to do those tasks"

Analysis suggests that participants get the basic or core care elements to address urgent health and care needs but not necessarily the help needed for living a fuller, more contented life. There was a sense of people ‘falling between the cracks’ in terms of needs not being met:

> “Because I am worse than a few years ago and I am still working and be a pedestrian, I am "still too good" to get help and support. This is a gap in the system”

There was also a reliance on a partner (or wider family), for those who lived with one:

> “My husband gives me all the support I need, and he has become my carer as my condition has got worse”
>
> “It is my spouse who helps me at home”

As suggested in the analysis of quantitative data, some participants agreed that this help from family and friends addresses their support needs partly or in full. However, others expressed the tension between being seen as ‘needy’ and the need/demand for more independence:

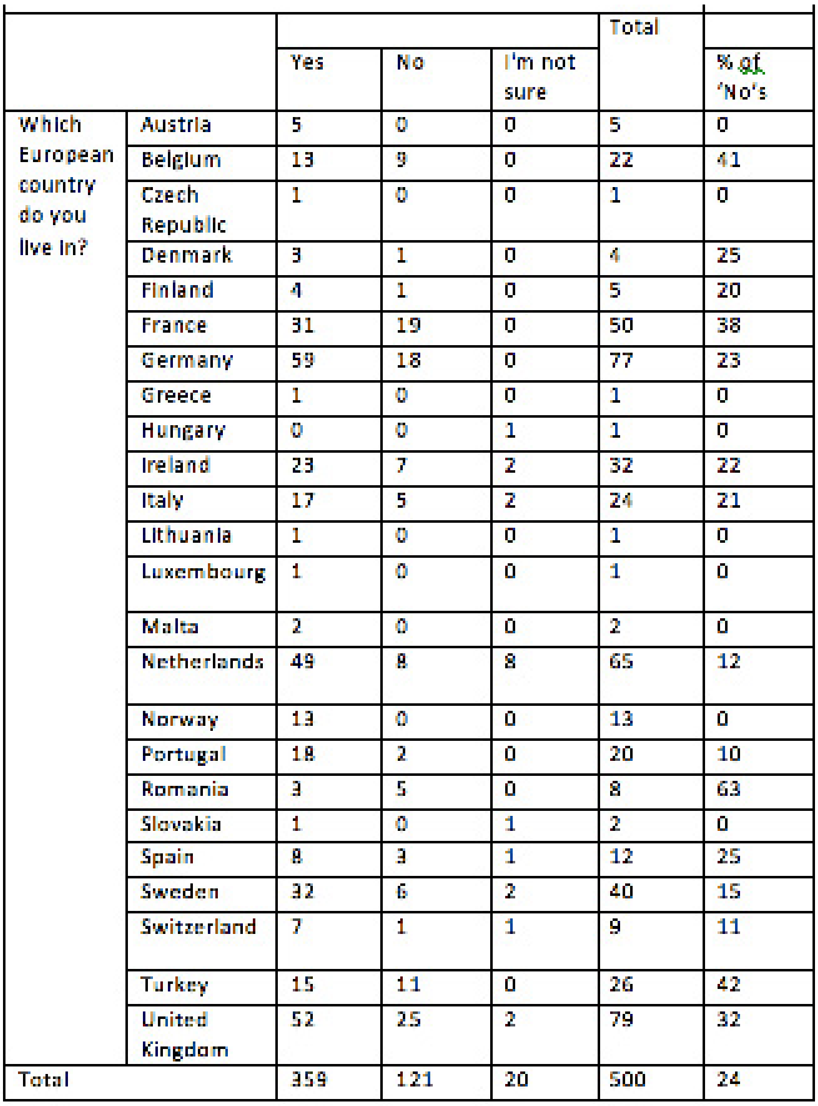
> “I would like to be in the condition of not depending on others”

The qualitative analysis paints a picture of a system that helps those whose disability requires assistance to address core care needs. However, beyond that, the system leaves many others struggling with completing tasks that relate to day-to-day life. This was noted from comments across Europe and was accompanied by consistent references to cuts in government spending, associated with the lack of desired help.

PARTICIPATION IN SOCIAL LIFE

Participants were asked if they regularly take part in social life of their choosing (such as culture, sports, outings with friends, travel, hobbies). The great majority (72%) are socially engaged but worryingly one person in four experiences social isolation. As can be seen in **Table 15** and based on responses, it is Turkey and Belgium where social isolation is rife whereas Portugal and Switzerland have the highest proportion of participants who are fully engaged in social activities. However, and as stated previously, the size of the sample and the recruitment strategy may limit the applicability of findings. Specifically here, the number of participants is as follows: Turkey n=42, Portugal n=20, Belgium n=26, Switzerland n=12. This statement of limitation applies to other parts of the report too.

Table 15 Country and social life tabulation



		Yes	No	I'm not sure	Total	% of 'No's
Which European country do you live in?	Austria	5	0	0	5	0
	Belgium	13	9	0	22	41
	Czech Republic	1	0	0	1	0
	Denmark	3	1	0	4	25
	Finland	4	1	0	5	20
	France	31	19	0	50	38
	Germany	59	18	0	77	23
	Greece	1	0	0	1	0
	Hungary	0	0	1	1	0
	Ireland	23	7	2	32	22
	Italy	17	5	2	24	21
	Lithuania	1	0	0	1	0
	Luxembourg	1	0	0	1	0
	Malta	2	0	0	2	0
	Netherlands	49	8	8	65	12
	Norway	13	0	0	13	0
	Portugal	18	2	0	20	10
	Romania	3	5	0	8	63
	Slovakia	1	0	1	2	0
	Spain	8	3	1	12	25
	Sweden	32	6	2	40	15
	Switzerland	7	1	1	9	11
	Turkey	15	11	0	26	42
	United Kingdom	52	25	2	79	32
Total		359	121	20	500	24

Participants were asked to reflect on their level of social activity in the past 5 years and consider the outlook for social interaction in 5 years hence. Unlike other facets of life the majority of participants (52%) noted a negative change to their social life activities, over a 5 year period, which they attributed to the ageing process. Considering such a deterioration, it is maybe unsurprising that half of participants anticipated a change to the worst, regarding social activities, in the next 5 years.

The question concerning the impact ageing with spina bifida or hydrocephalus has on intimate relationships, was also included in this cluster of questions. Participants were asked to consider impact on the relationship with a spouse, partner or potential partners and half of them reported no change. Yet a significant proportion (41%) stated that it is more difficult to access or enjoy intimate relationships than before. It is important to note that many more participants (n= 163) did not complete this question (Q 31) and they either skipped or exited the survey at this stage.

Although a specific question on changes in intimacy was included, mentions of 'sex' were noted throughout the survey, as captured in **Figure 12 (Appendices)**. It is important to note that as part of the ageing process, people may experience a decline in libido, but there were further challenges noted by participants. Specifically, pain and incontinence were both mentioned as barriers to sex, making it "difficult". This was clearly a source of unhappiness for the people and whilst a gradual decline in libido might be unavoidable, this is not necessarily the case for pain and incontinence.

The overall sense of deteriorating health, gleaned from analysis of all qualitative data, suggests that the manifestation of ageing is accelerated in people with SBH. The increased physical difficulty had knock-on effects on mental health and social engagement, which are in themselves related concepts.

> "I am more tired and weary so I participate less (to social life)"
>
> "I have more difficulties to move and walk therefore I make less social plans"
>
> "… exhaustion and pains progressively cut myself off from my family and friends. I am more and more isolated"

Many people described the importance of their social lives to them. The word cloud in **Figure 13 (Appendices)** shows the variety of activities that respondents were engaged in. Several acknowledged that this entailed an effort but that they saw it as important in living a fulfilled life:

> "You have to take care of offers and not isolate yourself"
>
> "Getting out with others, and a positive attitude also help"

There was also specific mention by several people of the role of support groups as a social activity. For example:

> "It's a very good thing to meet other people with the same trouble. And also to have tips and advice about ones rights etc"

Given the importance of social engagement, it is perhaps not surprising that there were many comments relating to the obstacles to it:

> “…my mobility and continence have deteriorated and
> I get far more tired now”

> “I try to get out as much as possible but worsening tiredness
> and general deterioration in health affects this and there are still lots
> of places are still inaccessible so cannot just ‘go out’ without some planning”

Fatigue or tiredness were also mentioned throughout the survey’s responses and were associated with a reduction in energy with pain and reduced work contacts and social activity. Socialising is indeed ‘difficult’ and it is possible to see how, for some, the physical changes attributed to ageing lead to the risk of negative cycle, increased isolation, and declining mental health.

HEALTH

The cluster of questions concerning health gave participants an opportunity to reflect on their physical as well as mental health. For a large proportion of participants (42%) most of the time their physical health was neither good nor bad. Yet, when asked to reflect on the previous 5 years, 70% of participants acknowledged that their overall health is worsening with one in four suggesting it is much worse now than previously. Mental health, on the other hand, was noted as good or 'pretty good' by 54% of participants (n=263).

Further specific aspects of health were explored by asking participants to consider their symptoms over a 5-year period. When asked about their experience of continence and pain, respectively, 35% and 38% of participants noted that these symptoms were getting worse. Worsening symptoms relating to the back /spine was experienced by 45% of the participants, but Hydrocephalus related changes were moderate. Thirteen percent of participants noted these as getting worse with 70% stating they observed no changes in the last 5 years.

Sleep and weight control were noted as deteriorating, but for the great majority (64%) of participants their skin remains intact and did not present a significant health challenge. A similar recording (57%) was noted regarding blood circulation with a deterioration corresponding to advancing in chronological age.

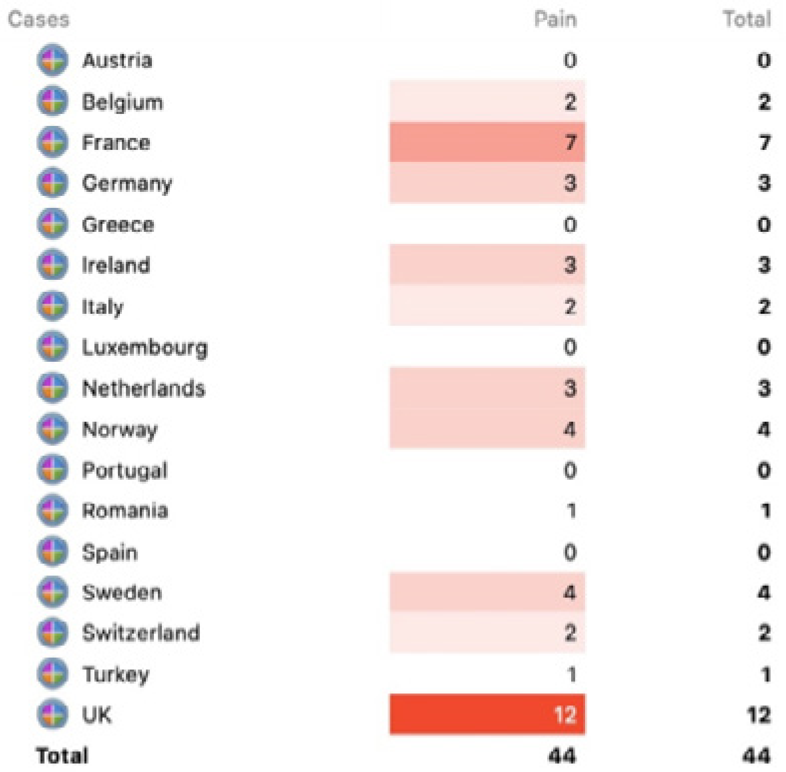
The qualitative analysis of narratives related to health, offered a unique insight that truly complemented these statistics. As can be seen in **Figure 14 (Appendices**), many comments were concerning deteriorating health. Many people mentioned reduction of mobility, struggles with continence and a general sense of decline:

> "I'm losing my physical strength more and more"
>
> "… as I get older I am struggling more as my mobility is deteriorating"
>
> "Everything is deteriorating"

Pain was another symptom prominently mentioned in additional text offered by participants. Analysis of the number of mentions by country in a heatmap (**Figure 15**) illustrates that a disproportionate number of mentions have come from the UK, which can only be partly explained by the UK sample size.

This cannot be explained as an artefact of translation, as pain (or synonyms) was used in responses from other countries but, as the heatmap shows, at a lower level. The reasons for this are not clear and require further exploration.

Figure 15 Pain heat map



Cases	Pain	Total
Austria	0	0
Belgium	2	2
France	7	7
Germany	3	3
Greece	0	0
Ireland	3	3
Italy	2	2
Luxembourg	0	0
Netherlands	3	3
Norway	4	4
Portugal	0	0
Romania	1	1
Spain	0	0
Sweden	4	4
Switzerland	2	2
Turkey	1	1
UK	12	12
Total	**44**	**44**

It is apparent that pain is a major issue for many people, often associated with a lack of energy or tiredness – indeed, chronic pain is exhausting! Yet it is unclear whether people are describing the same thing – for example joint pain, neuropathic pain etc.

> "Pain all over everyday"
>
> "Pains and exhaustion punctuate the social life"
>
> "My main problem is pain, if it were easier to get under control, I would be fine"

Increased problems with continence was another theme identified across the survey. It has impacts on a number of areas of life, sometimes quite profoundly:

> "I finished employment when my Continence deteriorated"
>
> "I have become incontinent again, therefore more difficult to be open to relationships"
>
> "Due to bowel and bladder problems I cannot plan to engage in any social activities as my toileting issues rule my life"

There is a clear picture emerging of increasing and all-consuming problems with continence that affects many aspects of life, see **Figure 16 (Appendices)**. Mentions of mental health throughout the survey responses are represented in **Figure 17 (Appendices)** where it is clearly noted that depression and anxiety are critical issues for many participants who noted the link between physical and mental health:

> “I've only developed mental health issues recently,
> partly due to my decreasing health”

> “I am suffering both physically and mentally right now.
> I cannot live the life in the way I want to”

> “I often feel misunderstood by some friends and family members
> and this society that does nothing to help us live like anyone else.
> I subsequently often experience sadness, anxiety, feelings of inferiority”

Some, on the other hand reported good mental health and the assets they possess to combat a sense of loneliness or isolation:

> “I’ve never had depression, and I don’t tend to.
> I am a positive thinking person”

> “I’m an optimistic person by nature!”

This is a reminder that everyone’s experience is different. Some people are just naturally positive about life and resilient to the challenges posed by ageing with spina bifida. However, others are not – and those challenges are having a deleterious effect on their mental health and quality of life.


QUICKIE

RESILIENCE

The emerging concept of resilience, which surfaced during the qualitative coding and analysis, is defined as 'the ability to withstand or recover from adversity'. We were able to combine a few 'child' themes relating to 'contentment': those aspects of life that people were happy with. 'Home suitability', 'Social engagement' and 'Support needs met' were themes that contributed to resilience, as can be seen in **Figure 18 (Appendices)**.

> "Continuing to take good care of yourself and staying active is extremely important"
>
> "Because we have to constantly grapple with our body and have to deal with changes or worsening, we have to learn to improve processes and can make life easier or what and whether you can do against worsening"

The narrative captured through the online survey paints a picture of life becoming difficult in several minor ways that add up to a more significant effect. Yet, not everyone conforms to such depiction of ageing, and participants noted that as they continue to look at ways to make life less difficult, they are also looking at strategies to cope better with the difficulties they face, in other words improve their resilience.

> "I love life and no matter if it's not easy it's worth it"
>
> "I have a positive attitude towards life and a second slogan in the family is: COUNT YOUR BLESSINGS!!!! And they are always there, but you do need to see them"
>
> "Trying again and again, without feeling despair, because in Turkey nobody would give a chance to people with disabilities. You get it by diligently forcing your way in"

DISCUSSION

As stated previously, the advancement in medical science, improved public health and rapid development of technologies had a significant impact on longevity. Demographic changes are evident globally and the number of older adults is increasing year on year. However, growing older is often associated with physiological changes, a decline in mental abilities, and for some, increased frailty, and ill health. Those growing older with the added complexity of living with a chronic condition, are more vulnerable to risks that may adversely affect their health and wellbeing. Uncovering these risks may be aided by understanding the developmental and lifespan transitions concerned with ageing.

The concept of transition, in the context of the older adults with SBH, involves a human response to change and associated needs. Within social science the emergent of a middle range theory[1] offers a lens with which to articulate the unique characteristics, core elements and patterns of response to complex and multidimensional experiences. To be in transition, a person must have some awareness of the physical, emotional, social, or environmental changes that are occurring and be engaged or involved in the process itself. Examples of engagement with transition[2] include seeking out information, using role models, actively preparing, and proactively modifying activities over time.

To fully understand a transition process, it is necessary to uncover and describe the effects and meanings of lived experiences over a period of time. The timeline may start with first signs of anticipation, perception, or demonstration of change and conclude with an eventual "ending", which is marked as a new beginning or a period of stability. Since transitions unfold over time, identifying indicators that move a person either in the direction of health or toward vulnerability and risk allows early assessment and planned intervention by designated agents. These could be employers, medical practitioners, social workers, or informal agencies such as national association staff. Such interventions must remain 'person centred' and ensure the wishes and desires of the individuals are taking into account when a dynamic and integrated package of support is constructed and offered.

Some indicators noted in the literature, to signal a healthy or meaningful transition process, include users' narrative that explicitly highlights: 'feeling connected', 'interacting', 'being situated', 'developing confidence' and 'coping'. Indicators of successful transition outcome include acquiring a sense of mastery regarding new skills, which are needed to manage a transition; and reconstruction of a valued self-identity. It is worth noting that all of these descriptors can be seen in the context of increased resilience, which emerged as an important theme in our analysis.

The study presented here focused on ageing and was seeking to articulate the lived experience of participants from across Europe.

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[1] Meleis, A.I., 2010. Transitions theory: Middle range and situation specific theories in nursing research and practice. Springer publishing company.

[2] Meleis, A.I., Sawyer, L.M., Im, E.O., Messias, D.K.H. and Schumacher, K., 2000. Experiencing transitions: an emerging middle-range theory. Advances in nursing science, 23(1), pp.12-28.

The data captured through the online survey enabled us to understand the way physical, emotional, social and environmental changes impact on people with SBH who are transitioning to or who are adjusting to being an older person.

For many younger participants, those who may not yet fully appreciate the journey they are facing, the initial indicator of change comes in the form of increased mobility challenges. These and other early presentations may be the indicator that preventative interventions are required to minimise risks to the individual.

As suggested by the transition framework, these younger participants should seek ways to be informed, be actively preparing, and proactively modifying activities to prepare for the future.

The older participants in our study are not only less mobile but are also more tired, in more pain, having more difficulty maintaining their physical space and the home environment. Analysis suggests that whilst progressing along the ageing pathway, people with SBH are becoming more isolated, their sex lives have deteriorated, and they are more anxious and depressed.

Whilst there were differences found between the various European countries and the way challenges were addressed, is was striking that many of the wide-ranging issues noted, required more than just a single intervention by one agency. Moreover, given the prominence of mental health issues in the data and the fact that the difficulties associated with ageing may increase the pressure on mental health, there may be a specific need for emotional support or counselling to be part of a holistic provision of care over a life time.

The transition framework reminds us that successful transition outcome includes active participation and acquisition or mastery of new skills. These may include strategies and ways to enhance a sense of resilience that could serve as a buffer to adversity that may be faced in the future.

The analysis of quantitative and qualitative data offer an insight into the lived experience of participants and an opportunity to consider ways to prevent or minimise the ill effect of ageing and share best practice. Yet, there are a few unanswered questions that could be explored further. For example: why is pain more prevalent in the UK responses? What is it that Sweden, The Netherlands and Switzerland are getting right about housing? How do some people develop resilience? In order to further our understanding, a more in-depth approach is required as a follow-up study.

RECOMMENDATIONS

The results demonstrate that there is a need to support and enhance the lived experience of people ageing with SBH across Europe. We suggest considering an integrated approach, on three levels, to address the challenges that a transition to old age herald:

European Social policy:

- Identify areas of best practice for transitional model of care for (older) people with neurological conditions such as SBH;
- Produce a detailed atlas of variation that collate maps with a narrative to identify and address unwarranted transitional care variation and support improvement in outcome across Europe;
- Encourage the development of personalised and holistic model of care for the older adult with SBH and sustainable and well informed workforce;
- Promote systems that can deliver information about transition to people with neurological conditions such as SBH;
- Advocate for a person-centred provision of services that include coordinated and integrated health and social care input;
- Consider introduction of legislation to enshrine the right for employment and meaningful occupation of those experiencing accelerated ageing;
- Develop a Europe wide campaign ‘OK to ask’ about sex aimed at the older person including those with SBH;
- Support further neurological research including further qualitative research on the impact of ageing and identification of outcome measures that are meaningful to people who are part of the SBH community

National – some activity may be channelled through national organisations:

- Facilitate engagement events to involve the community and co-produce education and information resources as part of a transition toolkit;
- Consider ways to enhance continence, pain management and sexual health issues for people with SBH as they age;
- Offer supplementary services to address the needs of adult as they transition to old age. Focus on emotional and mental health services where demand outstrips supply;
- Develop training content for professionals, carers and service users on transition to old age and building resilience skills;
- Support the needs of carers for and partners of those with SBH who transition to old age.

Individual:

- Engage in activities that enhance knowledge and skills of transitioning to old age;
- Hone resilience skills through enrolment in appropriate training, perhaps provided by national organisations, and through the use of self-directed resources;
- Consider ways to modify activities over time to address anticipated changes due to ageing.

ACKNOWLEDGEMENTS

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A special mention goes out to Cato Lie (Ryggmargsbrokk- og hydrocephalusforeningen, Norway), Mario Sel (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus, Belgium), Teije Dijk (SBH Nederland, the Netherlands), Benoit Fourcroy (Association Nationale Spina Bifida et Handicaps Associés, France), Jürgen Wolters and Bastian Schmatz (Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband, Germany), Giulia Bizzotto (Associazione Spina Bifida Italia), André Laia Teixeira (Associação Spina Bifida e Hidrocefalia de Portugal), Adriana Tontsch (Asociatia Romana de Spina Bifida si Hidrocefalie, Romania), Andrej Drdul (Slovenská spolocnosi´ pre spina bifida a/alebo hydrocefalus, Slovakia), Elisabet Maldonado (Associació Catalana d'Espina Bífida i Hidrocefàlia, Spain), Renée Höglin (Spin-off, Sweden), and Papatya Alkan Genca (Spina Bifida Dernegi, Turkey), who kindly volunteered to translate the survey into their national language. IF is particularly thankful to those who invested a great amount of their personal time to translate the many open answers back to English.

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Last but not least, IF would like to thank all its member organisations and the SBH community for taking the time to fill in and share the survey. Their feedback has been essential for the development of this report.

APPENDICES

Table 1 Which European country do you live in?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Austria	10	1.5	1.5	1.5
	Belgium	27	4.2	4.2	5.7
	Cyprus	1	.2	.2	5.8
	Czech Republic	1	.2	.2	6.0
	Denmark	5	.8	.8	6.8
	Finland	10	1.5	1.5	8.3
	France	69	10.6	10.6	18.9
	Germany	98	15.1	15.1	34.0
	Greece	2	.3	.3	34.3
	Hungary	3	.5	.5	34.8
	Ireland	43	6.6	6.6	41.4
	Italy	41	6.3	6.3	47.7
	Lithuania	1	.2	.2	47.8
	Luxembourg	1	.2	.2	48.0
	Malta	3	.5	.5	48.5
	Netherlands	74	11.4	11.4	59.8
	Norway	17	2.6	2.6	62.5
	Poland	1	.2	.2	62.6
	Portugal	20	3.1	3.1	65.7
	Romania	10	1.5	1.5	67.2
	Slovakia	2	.3	.3	67.5
	Spain	18	2.8	2.8	70.3
	Sweden	46	7.1	7.1	77.4
	Switzerland	13	2.0	2.0	79.4
	Turkey	43	6.6	6.6	86.0
	United Kingdom	91	14.0	14.0	100.0
	Total	650	100.0	100.0	

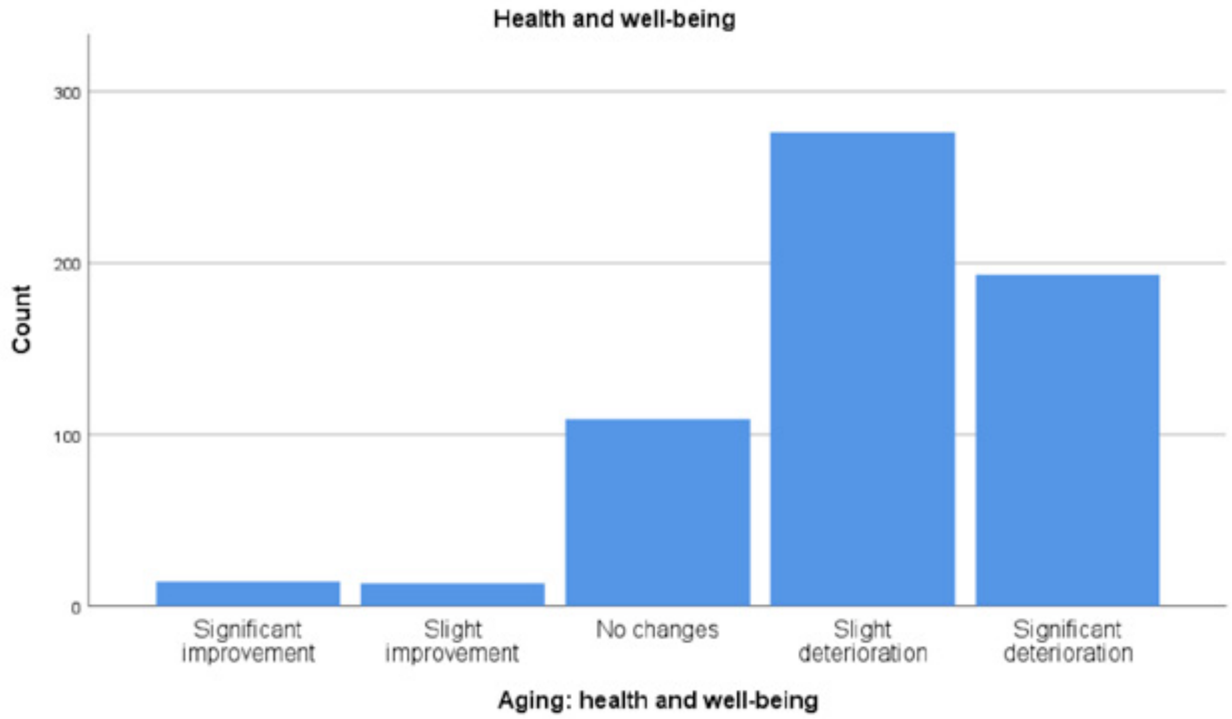


Figure 4 Overal health and wellbeing

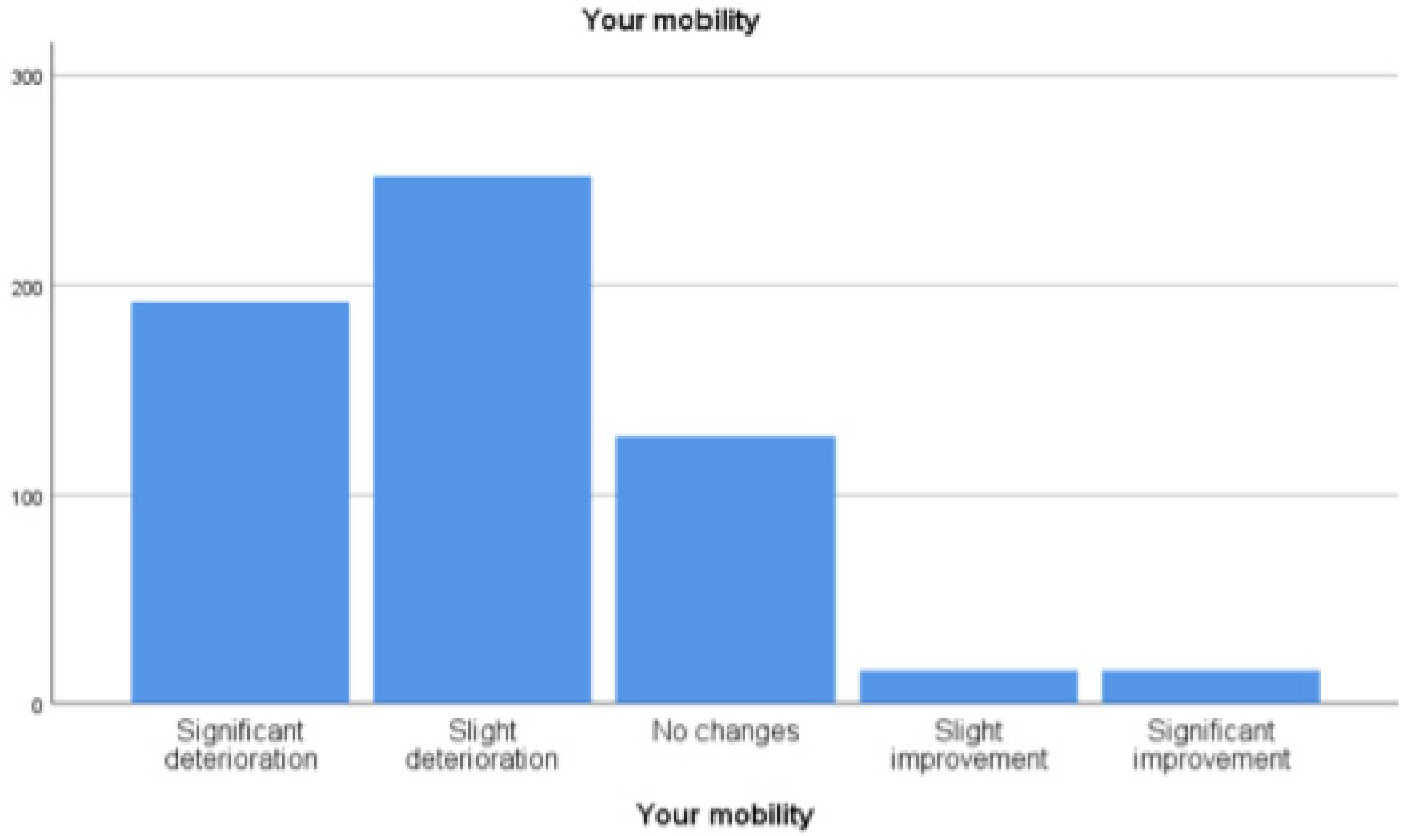


Figure 5 The impact of ageing on mobility

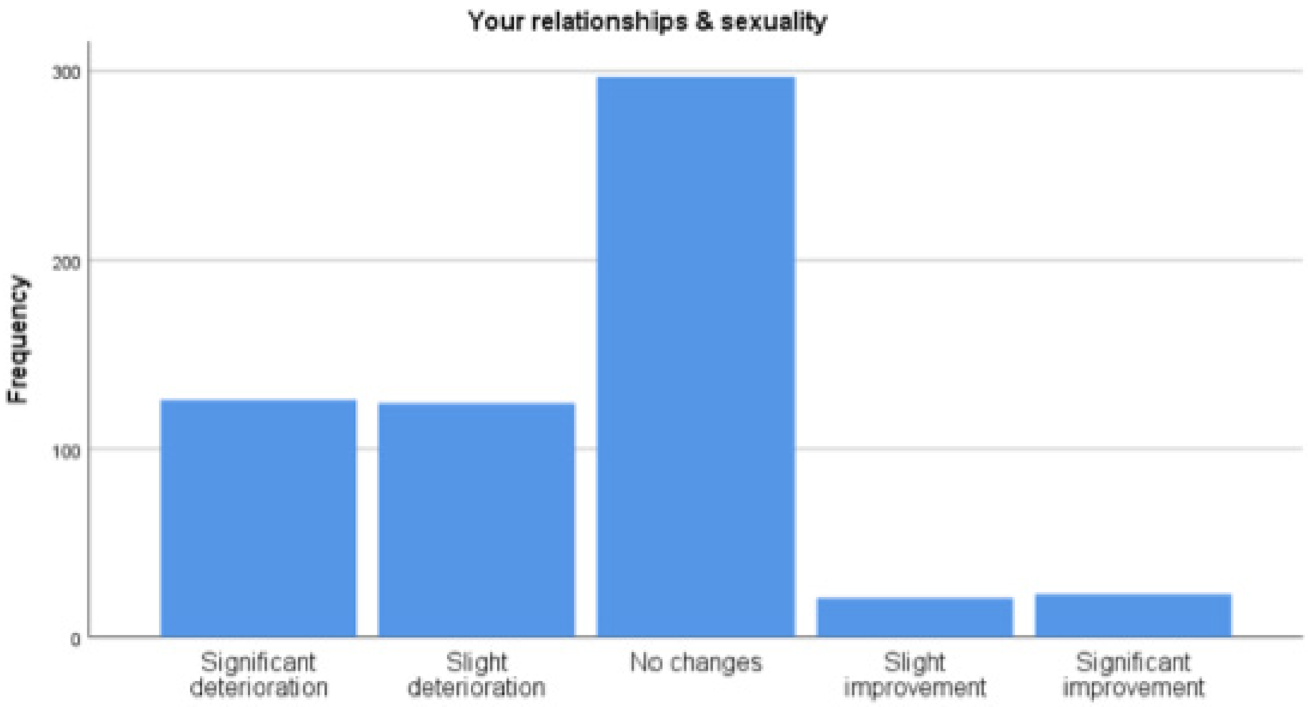


Figure 6 Relationship and sex

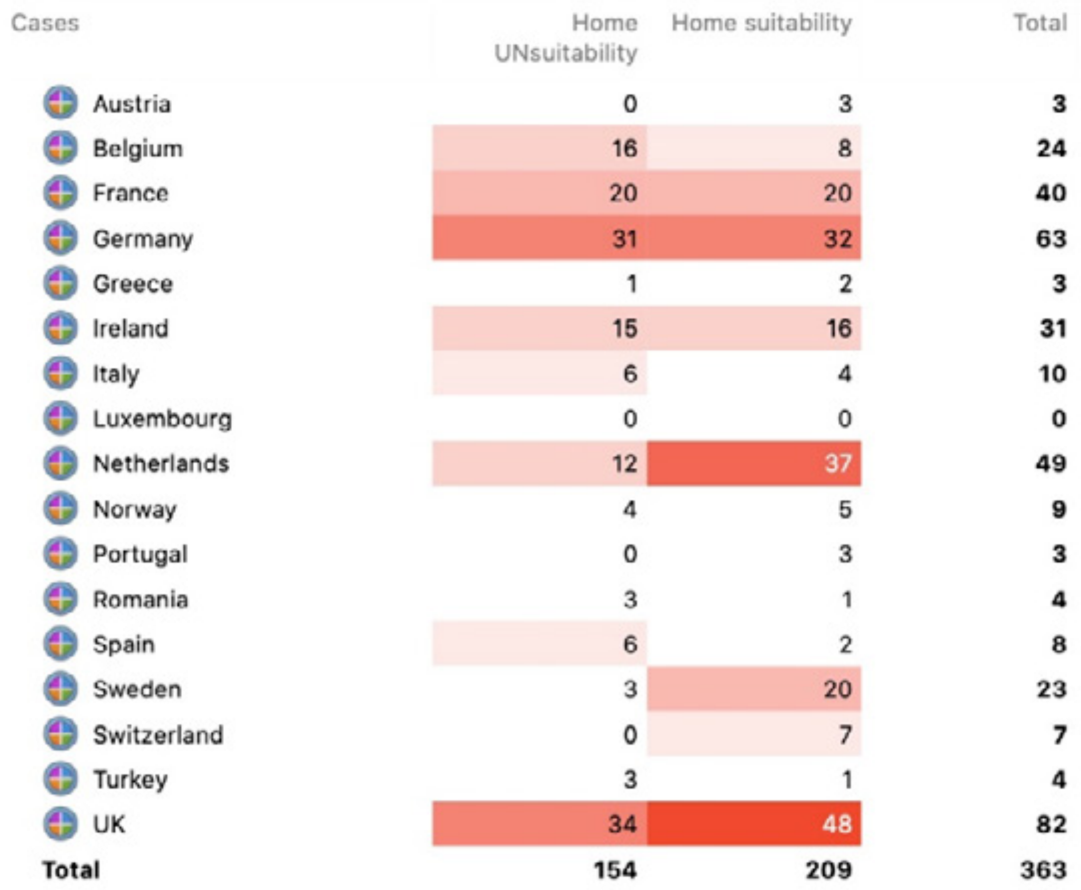
Table 7 Age and relationship / Sexuality

		Your relationships & sexuality					
		Significant deterioration	Slight deterioration	No changes	Slight improvement	Significant improvement	Total
What is your age? Please check the appropriate box.	35-44	48	53	159	13	17	290
	45-54	46	41	96	6	5	194
	55-64	22	22	36	2	1	83
	65+	10	8	6	0	0	24
Total		126	124	297	21	23	591

Table 8 Aae and social life

		Your social life					
		Significant deterioration	Slight deterioration	No changes	Slight improvement	Significant improvement	Total
What is your age? Please check the appropriate box.	35-44	39	73	140	20	23	295
	45-54	41	63	74	8	11	197
	55-64	14	30	30	4	5	83
	65+	10	8	6	0	0	24
Total		104	174	250	32	39	599

Figure 7 Home UNSuitability word cloud



Cases	Home UNsuitability	Home suitability	Total
Austria	0	3	**3**
Belgium	16	8	**24**
France	20	20	**40**
Germany	31	32	**63**
Greece	1	2	**3**
Ireland	15	16	**31**
Italy	6	4	**10**
Luxembourg	0	0	**0**
Netherlands	12	37	**49**
Norway	4	5	**9**
Portugal	0	3	**3**
Romania	3	1	**4**
Spain	6	2	**8**
Sweden	3	20	**23**
Switzerland	0	7	**7**
Turkey	3	1	**4**
UK	34	48	**82**
Total	**154**	**209**	**363**

Figure 8 Heat Map Home UNSuitability

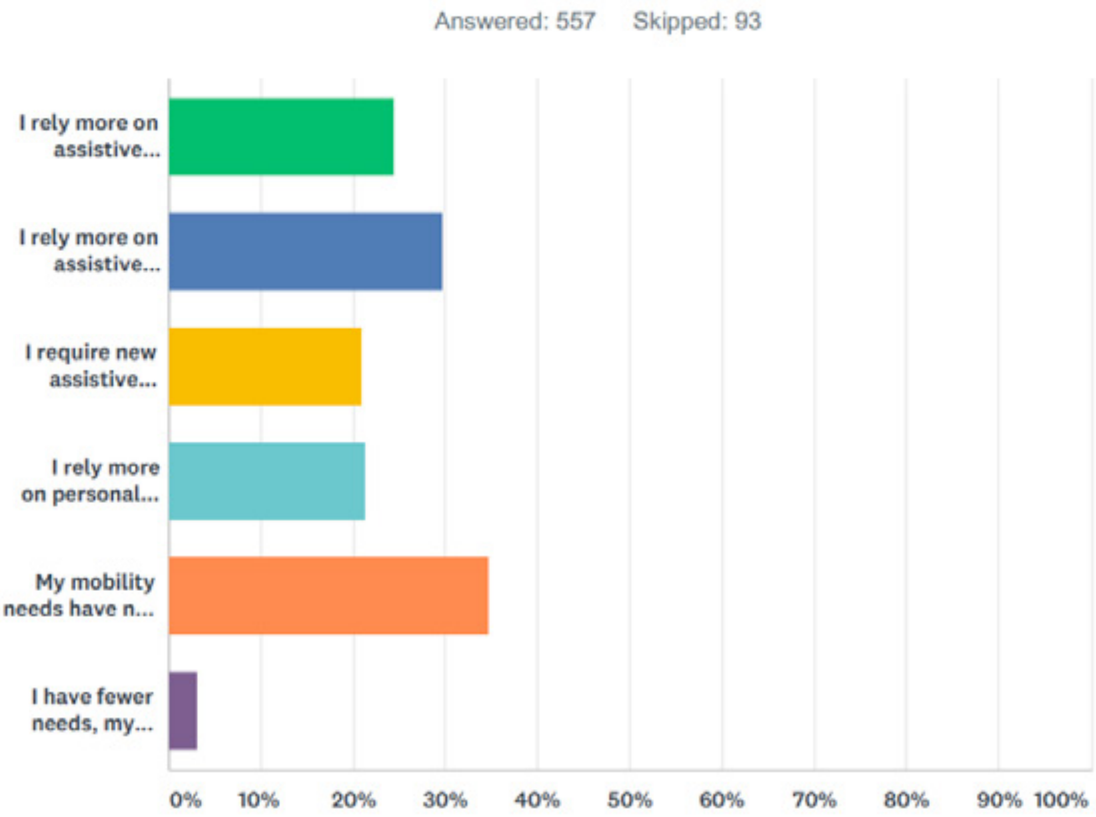


Figure 9 Changes to mobility needs over the last 5 years

Figure 12 Mentions of Sex as a word cloud

Figure 13 Social activity word cloud

Figure 14 Physical Health word cloud

Figure 16 Continence word cloud

Figure 17 Mental health word cloud

Figure 18 Resilience word cloud

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