



IF SURVEY

Ageing with spina bifida and hydrocephalus

Interim report

Background

In as early as 2012, IF published a position paper on ageing calling for a rapid and coordinated approach:

“It is imperative that policy makers take urgent action to combat the problems faced by people with Spina Bifida and Hydrocephalus as they age. They are the first with these conditions to reach their senior years and want to enjoy their older years in the same manner as other people their age.”

The evidence in which the paper was based included data collected from a range of stakeholders and an online survey (n=52).



Context

As we embark on what the World Health Organization's (WHO) coins a *Decade of Healthy Ageing* (2020-2030), it is important to evaluate progress 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.

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



Quantitative (numbers) and Qualitative (text) data

The survey was divided into several segments and included the following questions:

“General information” (q1-6),

“General overview” (q7),

“Right to appropriate housing of your choice” (q8-11),

“Right to personal mobility” (q12-15),

“Right to employment” (q16-22),

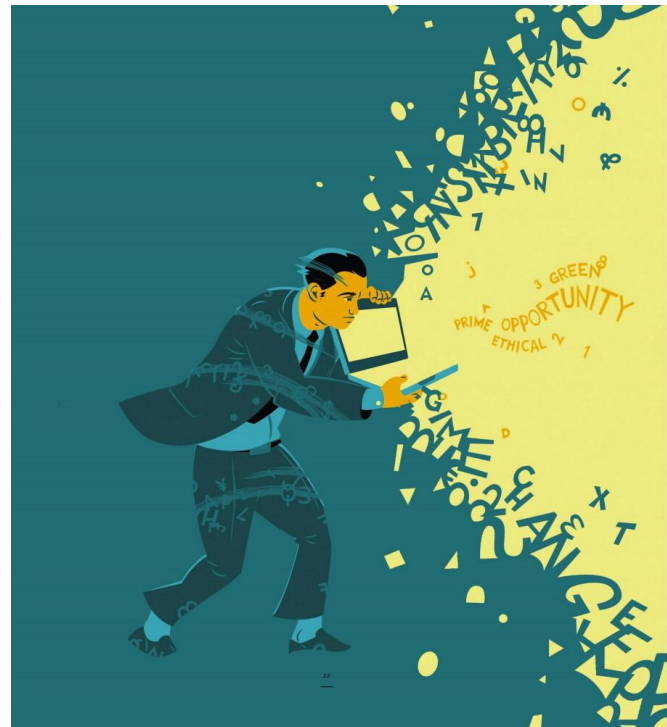
“Right to access, to support and to social protection” (q23-27),

“Right to participate in the life of the society” (q28–31),

“Right to health” (Q32–36) and

“Additional information” (q37-39).

Participants had an opportunity to choose an answer from a range of options and add free text.

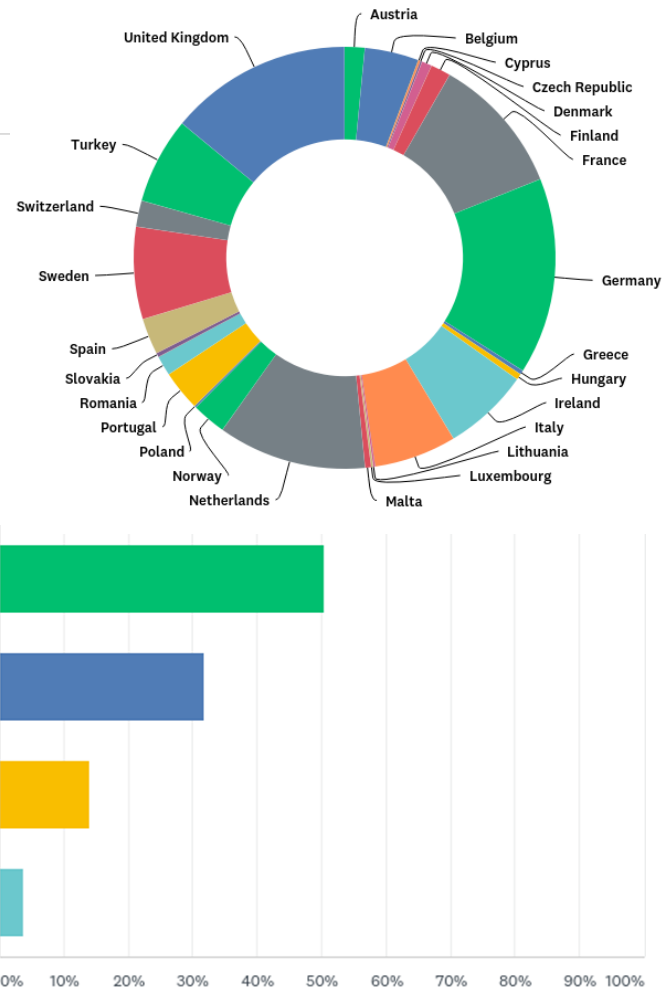


The sample

The survey went 'live' using a commercial online portal (www.surveymonkey.com) on the 17th of June 2019 and closed at the end of September that year.

Participants (n=650) came from 26 countries across Europe with the largest cohort coming from Germany (15.1%) and the UK (14%), followed by the Netherlands (11.4%) and France (10.6%).

We used a convenience sampling (non random or stratified per population) and the majority of participants (n=328, 50.46%) were those with an age range of 35-44 years.



Analysis and preliminary results

Results from quantitative data analysis was presented to those attended the workshop in Ghent and feedback informed further analysis.

Many more women (n=402 , 61.85%) participated in this survey and the education attainment of the great majority of participants is high school education with a large number progressing further and graduating from University.

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 “Hydrocephalus Only” category.

The majority (54%) of participants were in full or part time employment.

REPORT IF EU WORKSHOP IN GHENT

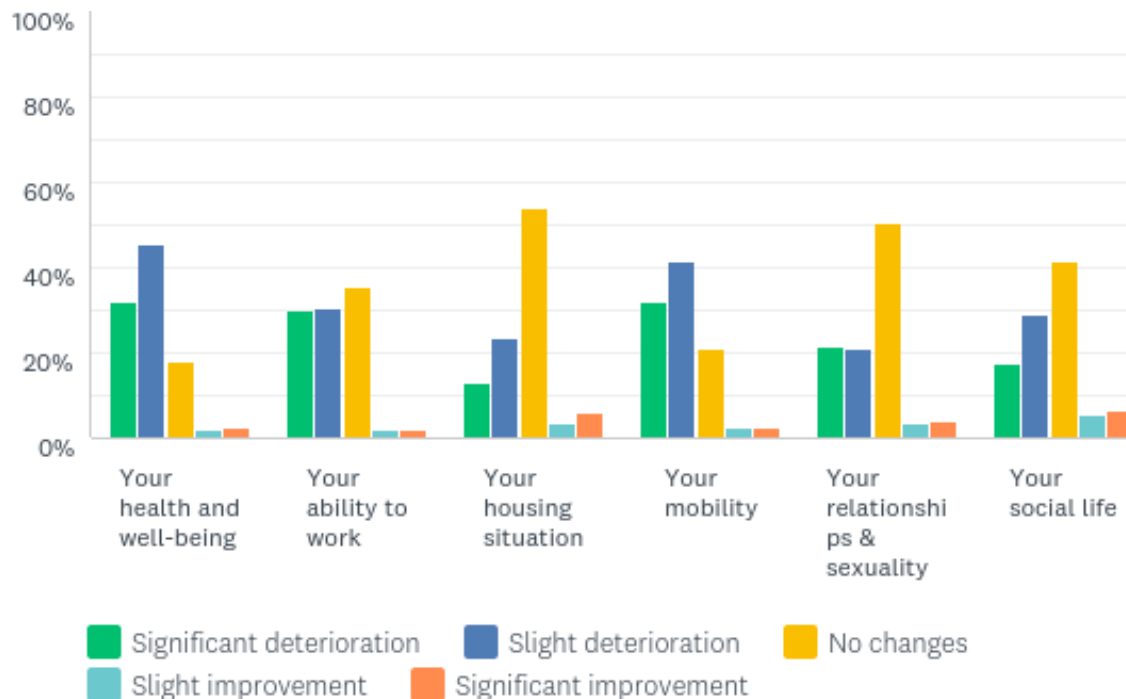
5 November 2019



General overview

Participants were asked to consider different facets of aging by responding to an early question about their

1. 'health and wellbeing'
2. 'ability to work'
3. 'housing'
4. 'mobility'
5. 'relationships / sexuality'
6. 'social life'.





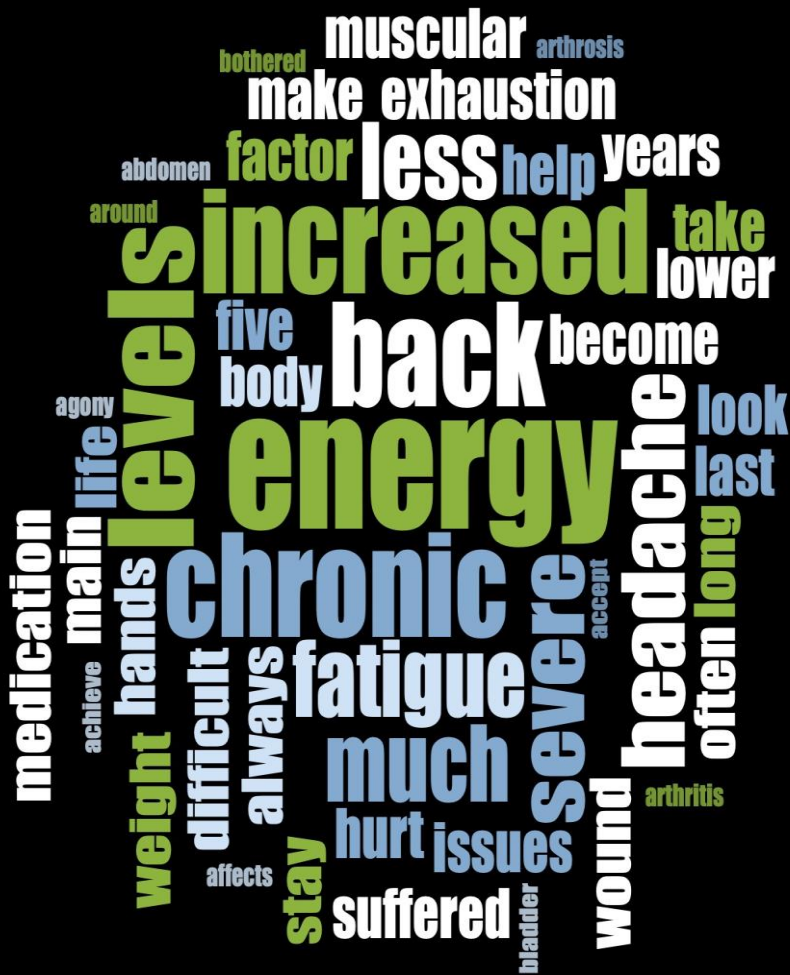
Pain

It is apparent that pain is a major issue for many people, often associated with a lack of energy or tiredness – chronic pain is exhausting:

“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.”



Mental Health

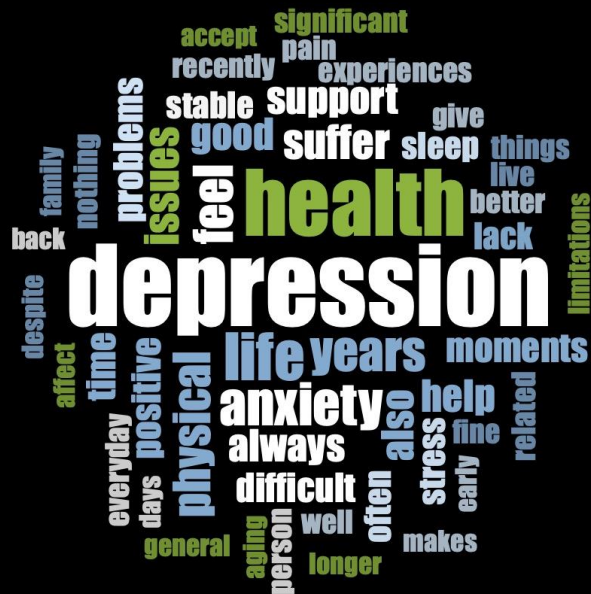
Clearly, depression and anxiety are critical issues for many participants who noted the link between physical and mental health:

"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 have 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!"



Mobility

When asked about mobility and the aging process a staggering 72% (n=444) of participants noted a deterioration or a severe deterioration in their condition.

There appear to be a correlation between age and deterioration of mobility: Only 20% amongst the younger participants attributed aging to a significant deterioration whereas 75% of the over 65 years old noted a significant deterioration.



Mobility * What is your age: Crosstabulation

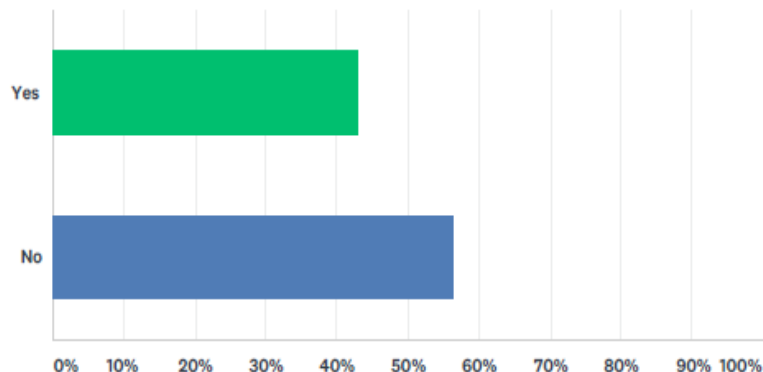
		35-44	45-54	55-64	65+	Total
Your mobility	Significant deterioration	(20%) 60	(37%) 74	(48%) 40	(75%) 18	192
	Slight deterioration	(44%) 130	(43%) 86	(36%) 30	(25%) 6	252
	No changes	(29%) 86	(16%) 31	(13%) 11	0	128
	Slight improvement	12	4	0	0	16
	Significant improvement	9	4	3	0	16
Total		297	199	84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

State aid and support

Q15 Do you receive adequate support from the government (or other agencies) for your changed personal mobility needs?

Answered: 554 Skipped: 96

Participants were asked about 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 most participants (50%) their support needs are fully covered by formal and/or informal agents or partly covered (32%).

The Netherlands stand out as a beacon of good practice with Turkey being the place with the highest proportion of participants whose needs are not being met.

Housing

Data show that the great majority of participants (92%) are living in a house or apartment and many of them live alone (n=230, 39%).

The majority (53%) of participants feel their home is suitable for their perceived age related needs.

However, the perception across Europe is somewhat different:

The majority of participants from Portugal (80%) Holland (79%) and Norway (71%) feel their home is suitable whereas participants in Belgium (29%) & Spain (24%) ranked their home as poor.

Participants from France (37%), Germany (41%) and Sweden (41%) ranked their home below the 50% mark too.


















Which European country do you live in? * Is your home suitable for your perceived age related needs? Crosstabulation

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

Home suitability

“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”

“If stairs become an issue in the future, we would need a house with bedroom and bathroom on the ground floor”

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

Number of items coded to Home suitability and home Unsuitability nodes, by country.

Home suitability

Narrative analysis began with the UK and Irish responses, before proceeding to that of the other countries.

This incremental addition of data allowed the identification of a unique distinction through a reference to a specific word.

It appears to sum up what people are happy with or would like to have: 'bungalow'.

A bungalow is a single story detached dwelling. However, as more data from other countries was added, it became less prominent in the word cloud.



Employment

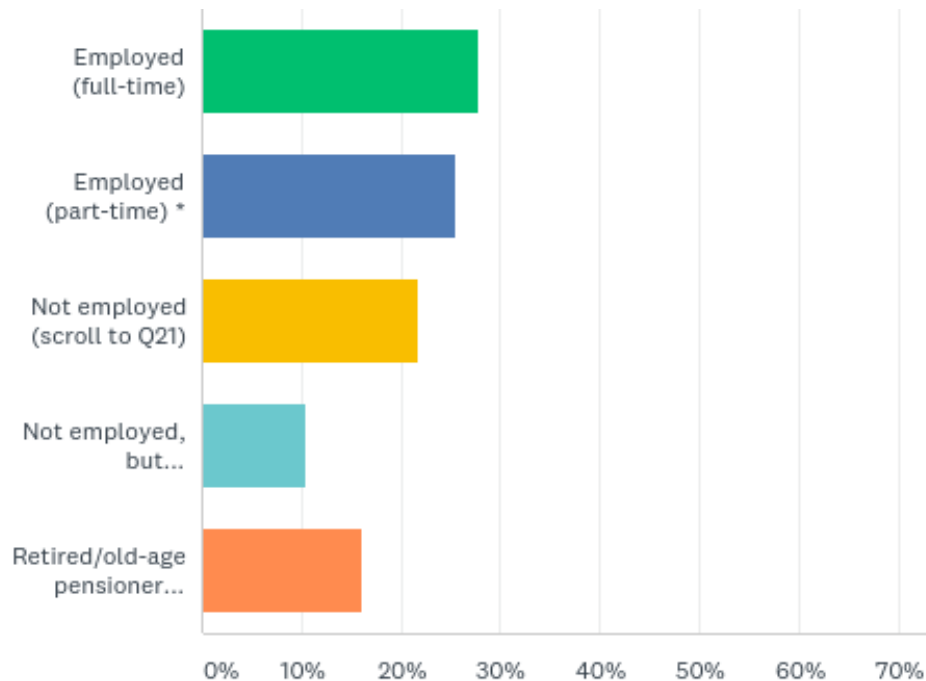
Answered: 551 Skipped: 99

There was a fairly even split between experiences of employment.

It is possible that for some respondents employment (and related to that, education) was an arena where the difficulties posed by spina bifida could be battled and overcome and perhaps therefore a source of affirmation. However, for many others finding employment was difficult and this was often directly related to the attitude of employers:

“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.”



Social participation

The great majority (72%) are socially engaged but worryingly one person in four is socially isolated.



Isolation and barriers to social engagement

It is possible to identify a trend where, for some, a negative cycle of increasing isolation and declining mental health becomes a major challenge.

“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”

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

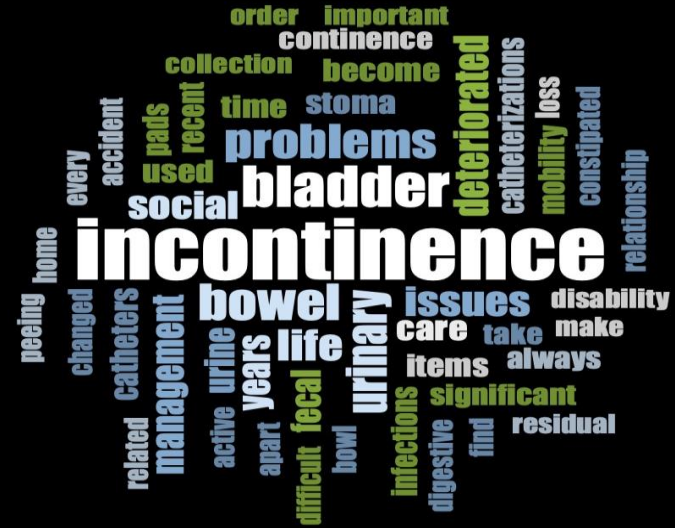


Incontinence

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

“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 here of increasing and all-consuming problems with continence that affects many aspects of life. This is reflected in the word cloud which makes plain the central problem of incontinence, which has come to dominate people's lives.



Intimacy & Sex

Participants were asked to consider impact on relationship with a spouse, partner or potential partners and the majority (49%) 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 exit the survey at this stage.

Specific mentions of sex throughout the survey were included. While there is generally considered to be a decline in libido as part of the aging process, there are further issues at play here, as the word cloud illustrates. Pain and incontinence are both indicated as barriers to sex. It is “difficult”.



Fatigue

There were a number of mentions of this concept associated with a reduction in energy as well as social and work activity. It was also often related to pain.

“I don’t have the strength to participate in social life when I’m working during the day. At weekends I can do a bit sometimes. But I’m losing my physical strength more and more.”

“Most of time then I can’t get to the pleasant things in life anymore, because then the day will be over and my strength diminish.”



Resilience

without suitable shower
activities support good
kitchen disabled meet built
lift friends years
concerts
bathroom
regularly
apartment group
adapted
live
care
needs floor
wheelchair
life home
sports moving
taking week
things
family
level
ground
works
help part
also
bungalow
social
stairs
assisted
travel
people
room
well
allows