

Dignity and decision-making: insights from the Global Lung Cancer Coalition's patient experience surveys

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Background

The Global Lung Cancer Coalition (GLCC) is a partnership of 42 patient organisations across 30 nations, dedicated to improving outcomes for lung cancer patients. Our members collaborate and campaign to improve lung cancer patients' experience of their treatment and care, both at a national level and globally.

To do this we need to understand what lung cancer patients experience, from the point of their diagnosis and as they progress through their treatment and care. Through our network of members we have run two global surveys, one in 2020 and one in 2021, to ask patients around the world about their lung cancer journeys. We are grateful to every patient and carer who has responded.

The importance of dignity and involvement in decision-making

We know that lung cancer patients can often face stigma due to lung cancer's association with smoking. The GLCC believes that no patient should experience stigma or shame, no matter the cause of their disease. Our Patient Charter sets out the rights that we believe all lung cancer patients should have, including the right of every patient to be treated with dignity and respect.

We also believe that lung cancer patients should be supported to understand and be fully involved in decisions about their treatment and care. Every patient is an individual, with their own needs, preferences and goals. Patients should be encouraged to share their views with their medical teams, so that their voice can inform and shape the decisions that are made about their treatment.

We therefore asked questions about these two important topics in our 2020 and 2021 patient surveys. Different countries participated in the two surveys, so for some countries we have data for both years and for some we only have data for one year. The findings give a snapshot of how respondents to these surveys feel and indicate areas where change is needed to improve patients' experiences or support them to be involved in their care.

Key findings and calls to action

Every country can be doing more to increase the proportion of lung cancer patients who feel they are always treated with dignity and respect by their care team. In most countries, there is a small proportion of lung cancer patients who feel they are only sometimes or never treated with dignity and respect by their care team.

Every country can be taking steps to increase the proportion of patients who feel they are fully involved in decision-making about their treatment and care. There is variation between countries in how involved lung cancer patients feel in decision-making, but no country has more than 75% of respondents saying that they feel fully involved.

Do lung cancer patients feel they are treated with dignity and respect by their treatment team?

In both surveys we asked patients the same question: ‘since your diagnosis, has your treatment team treated you with dignity and respect?’ We gave people four options to choose from: always, mostly, sometimes and never. The table below sets out their responses. Please note that, in some countries, the small number of responses affects the percentages.

Table 1: 2021 and 2020 survey responses to the question ‘Since your diagnosis, has your treatment team treated you with dignity and respect?’

		Always		Mostly		Sometimes		Never	
		2021	2020	2021	2020	2021	2020	2021	2020
Taiwan	%	73%	-	22%	-	4%	-	1%	-
	n	387	-	119	-	21	-	5	-
Netherlands	%	83%	70%	11%	23%	5%	5%	1%	1%
	n	144	105	19	34	9	8	2	2
USA	%	78%	75%	19%	23%	3%	2%	0%	0%
	n	103	31	25	8	4	1	0	0
Italy	%	68%	-	14%	-	13%	-	4%	-
	n	71	-	15	-	14	-	4	-
Denmark	%	64%	57%	33%	35%	3%	9%	0%	0%
	n	42	13	22	8	2	2	0	0
Brazil	%	84%	76%	13%	17%	2%	5%	2%	2%
	n	46	100	7	22	2	6	1	3
UK	%	72%	65%	21%	23%	6%	11%	2%	1%
	n	38	70	11	29	3	14	1	2
Canada	%	71%	65%	20%	28%	6%	4%	2%	2%
	n	35	30	10	13	3	2	1	1
Spain	%	81%	75%	16%	20%	2%	6%	0%	0%
	n	35	50	7	13	1	4	0	0
Ireland	%	54%	57%	29%	30%	4%	11%	13%	3%
	n	13	21	7	11	1	4	3	1
Portugal	%	92%	100%	8%	0%	0%	0%	0%	0%
	n	22	16	2	0	0	0	0	0
Australia	%	82%	66%	18%	26%	0%	8%	0%	0%
	n	9	25	2	10	0	3	0	0
Mexico	%	67%	83%	33%	17%	0%	0%	0%	0%
	n	4	34	2	7	0	0	0	0
South Africa	%	75%	-	25%	-	0%	-	0%	-
	n	3	-	1	-	0	-	0	-
Bulgaria	%	0%	53%	0%	0%	0%	26%	100%	20%
	n	0	8	0	0	0	4	1	3
Sweden	%	0%	44%	100%	41%	0%	11%	0%	5%
	n	0	39	1	36	0	9	0	4
Greece	%	0%	-	0%	-	100%	-	0%	-
	n	0	-	0	-	1	-	0	-
Iceland	%	0%	-	100%	-	0%	-	0%	-
	n	0	-	1	-	0	-	0	-

The results show that more can be done in every country to make sure that lung cancer patients feel they are always treated with dignity and respect by their treatment team.

In 2021, the country with the largest proportion of respondents saying they felt treated with dignity and respect was Portugal, with 92% (22 people). Portugal also had the largest proportion in 2020, when 100% (16 people) said they were always treated respectfully by their treatment team.

In 2021, there were a further four countries where more than eight in ten respondents said they felt they were always treated with dignity and respect: the Netherlands (83%, 144 people), Brazil (84%, 46 people), Spain (81%, 36 people), and Australia (82%, nine people).

In most countries, however, there was a small number of respondents who said they were only sometimes or never treated with dignity and respect by their treatment team.

We encourage all countries to examine these findings and to consider:

- If they are representative of the lung cancer patient population in their country
- What more can be done to increase the proportion of lung cancer patients who feel they are always treated with dignity and respect by their treatment team

Do lung cancer patients feel involved in decision-making about their treatment and care?

We asked patients the same question in both the 2021 and 2020 surveys: *'When talking to your treatment team, did you feel involved in the decisions about your treatment and care?'*

In 2020, we asked patients to choose between four options:

- Yes
- No
- No, but I didn't want to be involved
- No, but my caregiver was involved

In 2021, however, we wanted to better understand the extent to which patients felt they had been or would like to be involved in decision-making. We therefore gave respondents additional options:

- Yes, I've been fully involved
- Yes, I've been involved most of the time
- Yes, I've been involved sometimes
- No, but I would like to be involved
- No, but I didn't want to be involved
- No, but my caregiver was involved

Table 2 below aggregates the answers that were a 'yes' so that we can compare findings for 2021 and 2020 surveys for those countries that participated in both.

Table 2: 2021 and 2020 survey responses to the question 'When talking to your treatment team, did you feel involved in the decisions about your treatment and care? Please choose the option that best describes you.'

		Yes		No		No, but I didn't want to be involved		No, but my caregiver was involved	
		2021	2020	2021	2020	2021	2020	2021	2020
Taiwan	%	88%	-	6%	-	2%	-	4%	-
	n	472	-	34	-	10	-	20	-
Netherlands	%	93%	86%	6%	11%	1%	1%	1%	1%
	n	161	128	11	17	1	2	2	2
USA	%	95%	92%	5%	6%	0%	0%	1%	2%
	n	125	48	6	3	0	0	1	1
Italy	%	75%	-	17%	-	4%	-	4%	-
	n	79	-	18	-	4	-	4	-
Denmark	%	80%	74%	14%	13%	2%	13%	5%	0%
	n	53	17	9	3	1	3	3	0
Brazil	%	82%	66%	7%	20%	4%	4%	7%	11%
	n	46	88	4	26	2	5	4	14
UK	%	89%	84%	7%	15%	2%	1%	2%	0%
	n	48	131	4	23	1	2	1	0
Canada	%	88%	79%	12%	15%	0%	2%	0%	4%
	n	43	38	6	7	0	1	0	2
Spain	%	84%	65%	12%	24%	2%	6%	2%	6%
	n	36	44	5	16	1	4	1	4
Ireland	%	79%	54%	21%	35%	0%	3%	0%	8%
	n	19	20	5	13	0	1	0	3
Portugal	%	91%	80%	8%	0%	0%	13%	0%	7%
	n	22	12	2	0	0	2	0	1
Australia	%	90%	71%	10%	18%	0%	5%	0%	5%
	n	9	27	1	7	0	2	0	2
Mexico	%	83%	59%	0%	5%	0%	2%	17%	34%
	n	5	24	0	2	0	1	1	14
South Africa	%	100%	-	0%	-	0%	-	0%	-
	n	4	-	0	-	0	-	0	-
Bulgaria	%	100%	53%	0%	27%	0%	0%	0%	20%
	n	1	8	0	4	0	0	0	3
Sweden	%	100%	54%	0%	34%	0%	6%	0%	6%
	n	1	47	0	30	0	5	0	5
Greece	%	100%	-	0%	-	0%	-	0%	-
	n	1	-	0	-	0	-	0	-
Iceland	%	100%	-	0%	-	0%	-	0%	-
	n	1	-	0	-	0	-	0	-

The table shows that most respondents in all countries felt that they were involved in decision-making to some extent. However, in most countries there was a small proportion of lung cancer

patients who did not feel involved in decisions around their care, and this is not because they don't want to be involved or because a caregiver is involved on their behalf.

The 2021 survey question sheds further light on this, with the additional options giving more insight into the extent to which lung cancer patients feel involved in decision-making. The findings for the 2021 survey question are set out in Table 3 below.

Table 3: 'When talking to your treatment team, did you feel involved in the decisions about your treatment and care? Please choose the option that best describes you.' 2021 responses only

		Yes, I've been fully involved	Yes, I've been involved most of the time	Yes, I've been involved sometimes	No, but I would like to be involved	No, but I didn't want to be involved	No, but my caregiver was involved
Taiwan	%	57%	21%	10%	6%	2%	4%
	n	305	113	54	34	10	20
Netherlands	%	75%	13%	5%	6%	1%	1%
	n	131	22	8	11	1	2
USA	%	66%	18%	11%	5%	0%	1%
	n	87	24	14	6	0	1
Italy	%	34%	26%	15%	17%	4%	4%
	n	36	27	16	18	4	4
Denmark	%	47%	24%	9%	14%	2%	5%
	n	31	16	6	9	1	3
Brazil	%	61%	14%	7%	7%	4%	7%
	n	34	8	4	4	2	4
UK	%	48%	22%	19%	7%	2%	2%
	n	26	12	10	4	1	1
Canada	%	49%	27%	12%	12%	0%	0%
	n	24	13	6	6	0	0
Spain	%	40%	19%	26%	12%	2%	2%
	n	17	8	11	5	1	1
Ireland	%	42%	17%	21%	21%	0%	0%
	n	10	4	5	5	0	0
Portugal	%	54%	29%	8%	8%	0%	0%
	n	13	7	2	2	0	0
Australia	%	60%	30%	0%	10%	0%	0%
	n	6	3	0	1	0	0
Mexico	%	33%	17%	33%	0%	0%	17%
	n	2	1	2	0	0	1
South Africa	%	75%	25%	0%	0%	0%	0%
	n	3	1	0	0	0	0
Bulgaria	%	0%	0%	100%	0%	0%	0%
	n	0	0	1	0	0	0
Sweden	%	0%	100%	0%	0%	0%	0%
	n	0	1	0	0	0	0
Greece	%	0%	0%	100%	0%	0%	0%
	n	0	0	1	0	0	0
Iceland	%	0%	100%	0%	0%	0%	0%
	n	0	1	0	0	0	0

Table 3 demonstrates that there is considerable variation both within and between countries in the extent to which lung cancer patients have been involved in decision-making around their treatment and care.

No country had more than three quarters of the respondents say that they were fully involved in decision-making. The countries with the largest proportions of patients feeling fully involved were the Netherlands (75%, 131 respondents) and South Africa (75%, three respondents), followed by the United States (66%, 87 respondents).

In most countries, a small proportion of respondents said that they had not been involved in decision-making but that they would want to be involved. This suggests more could be done to improve and support some lung cancer patients to become involved in decision-making.

We encourage all countries to examine these findings and to consider:

- If they are representative of the lung cancer patient population in their country
- What actions can be taken by treatment teams to ensure that all lung cancer patients have the opportunity to be involved in decisions around their treatment and care
- What support can be provided to enable an increase in the proportion of lung cancer patients who feel they are fully involved in decision-making

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Contact us

Established in 2001, the GLCC comprises 42 non-government patient organisations from 30 nations: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, Greece, Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Peru, Portugal, Russia, Slovenia, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey, UK and USA.

The GLCC promotes global understanding of lung cancer and the right of patients to effective early detection, better treatment, and supportive care. By serving as the international voice of lung cancer patients, the GLCC is committed to improving disease outcomes for all.

For more information about this study and the work of the GLCC please visit: www.lungcancercoalition.org or email our secretariat at: glcc@roycastle.org