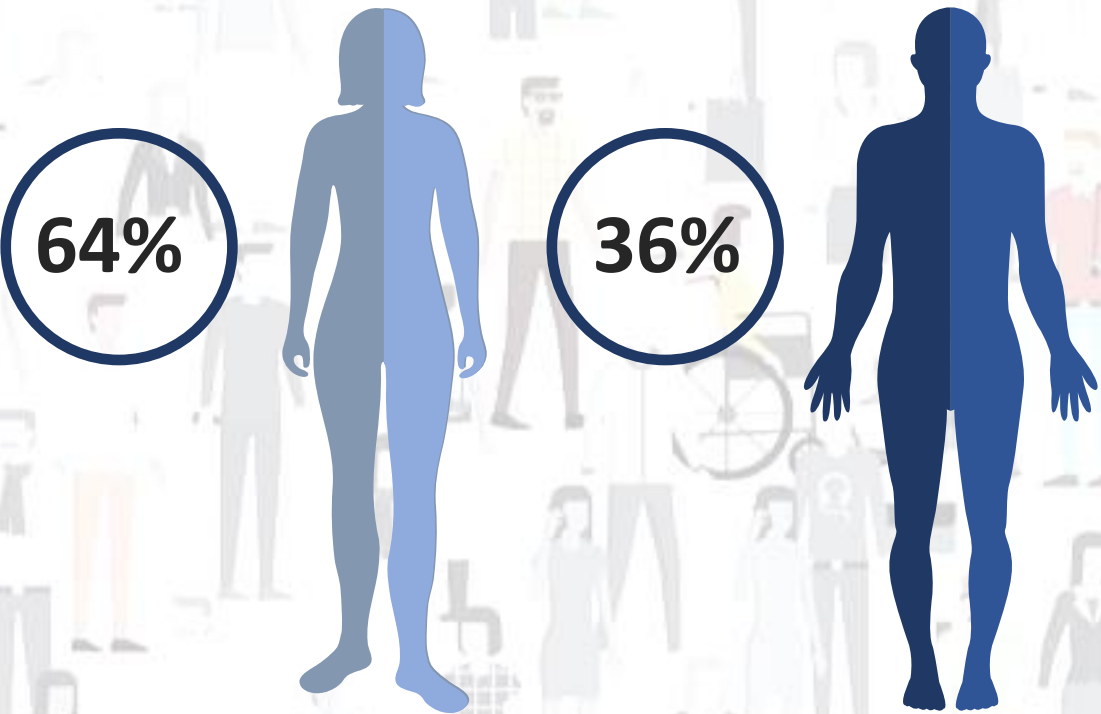
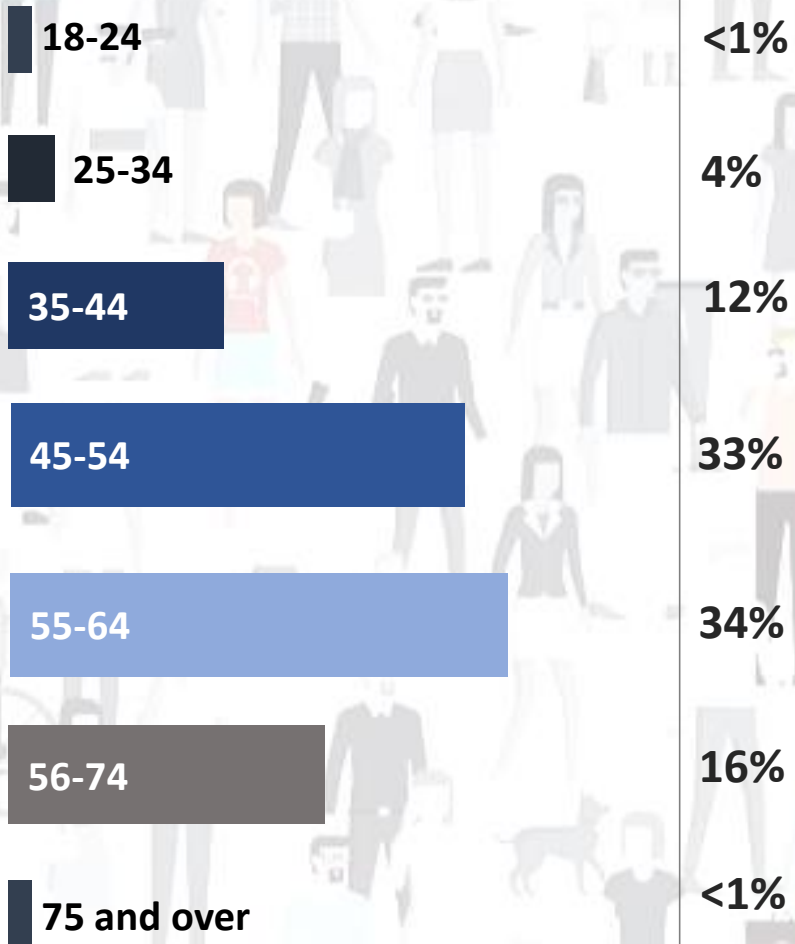




Cancer Survey 2018

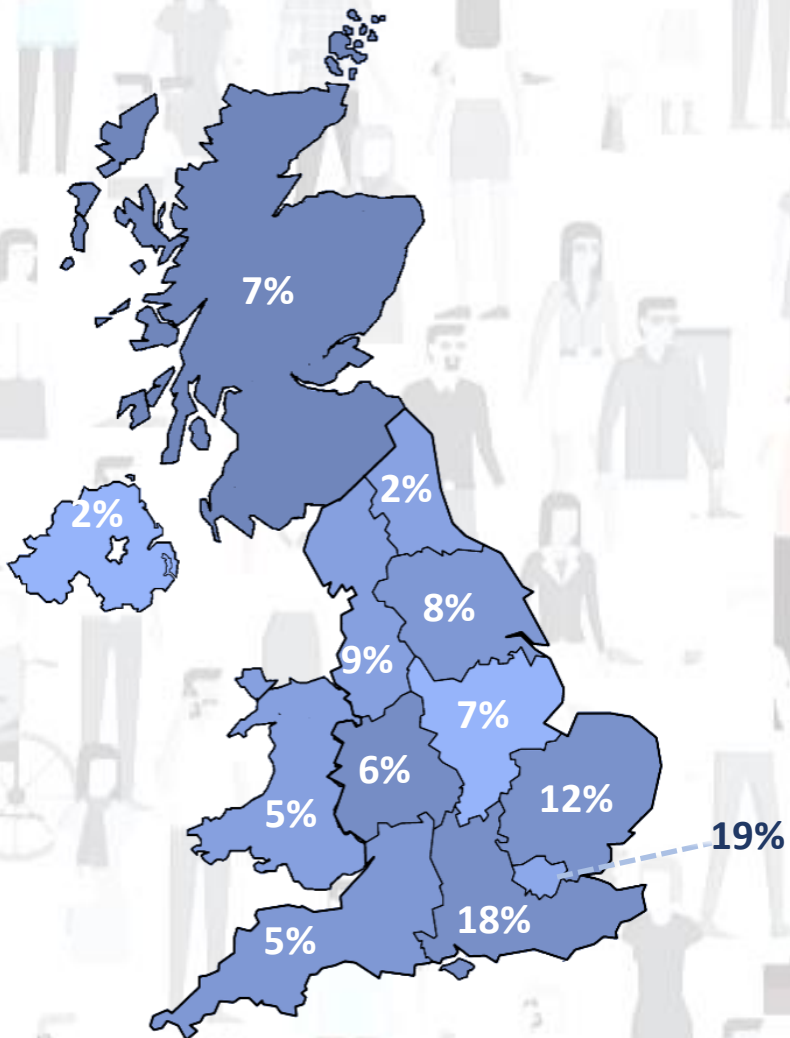
LDA Research Ltd.

Demographics



N=413

Demographics



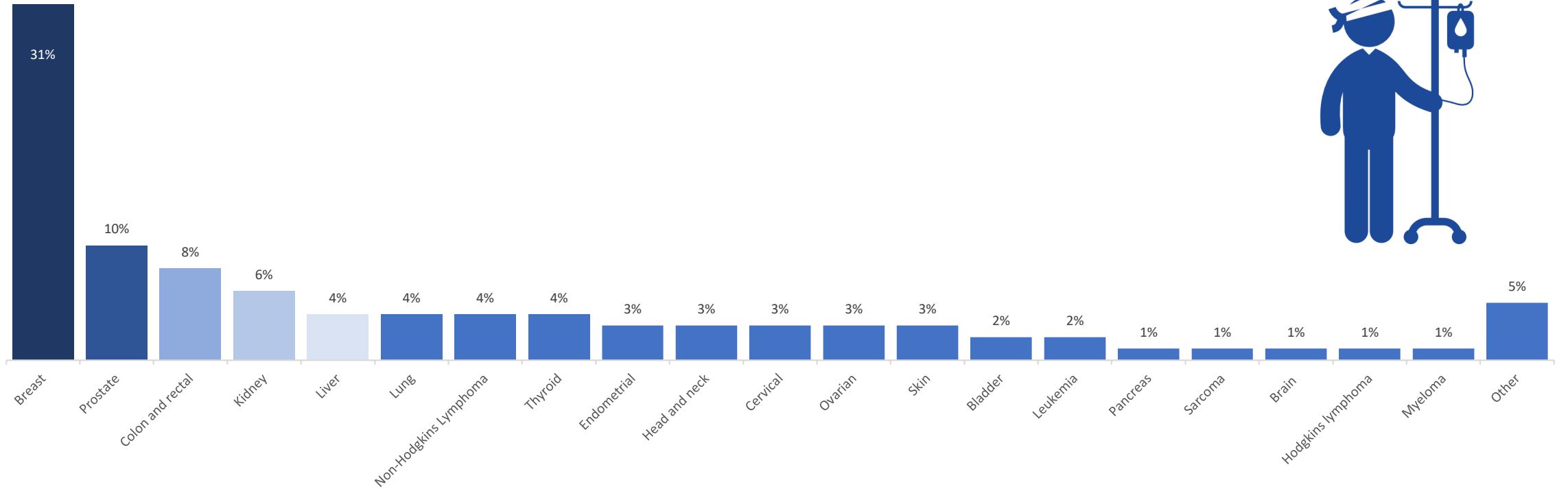
White – 94%

Asian / Asian British 2%

Black / African / Caribbean / Black British 2%

Mixed / Multiple ethnic groups 2%

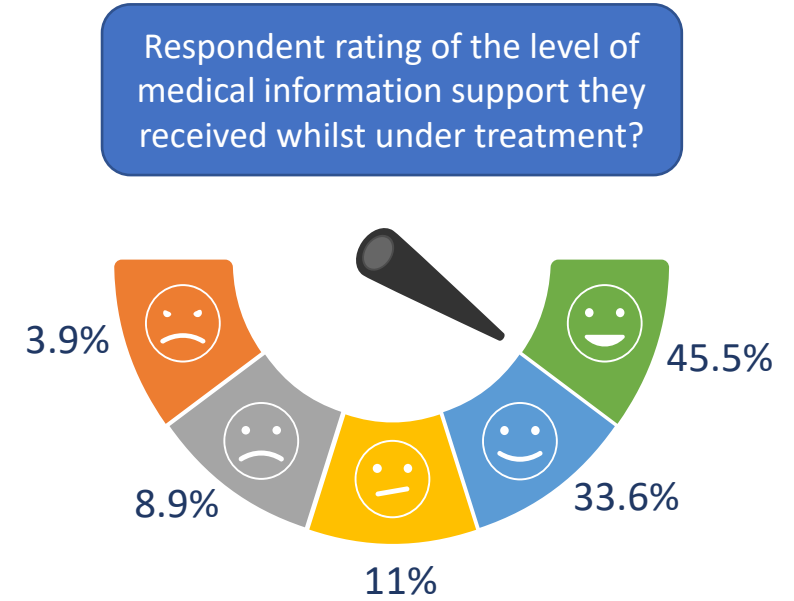
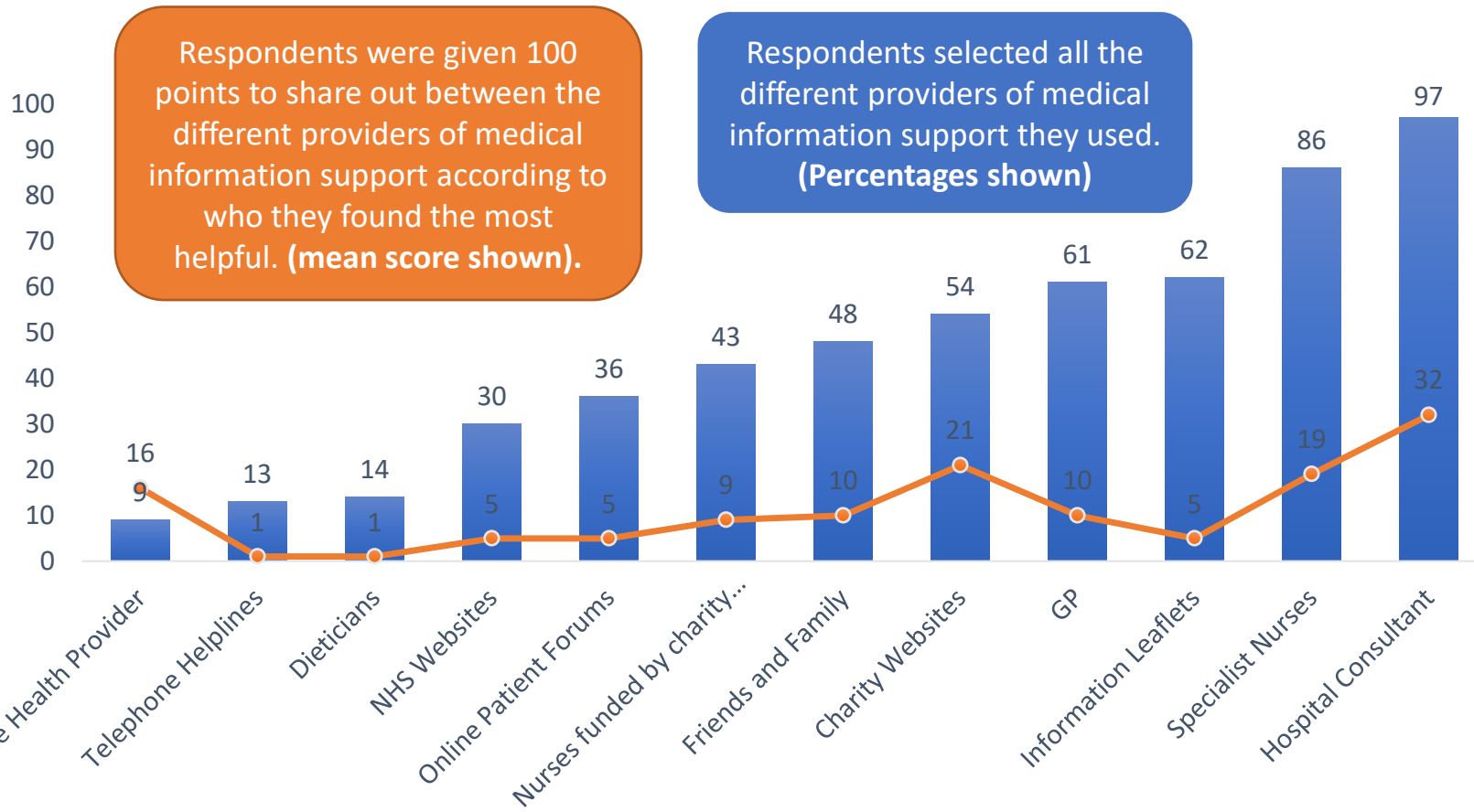
What type of cancer have you been diagnosed with?



N=413

Medical Information Support Definition - Information about treatment, information about diagnosis, support with questions about treatment and diagnosis, support and information about managing secondary conditions, dietary information.

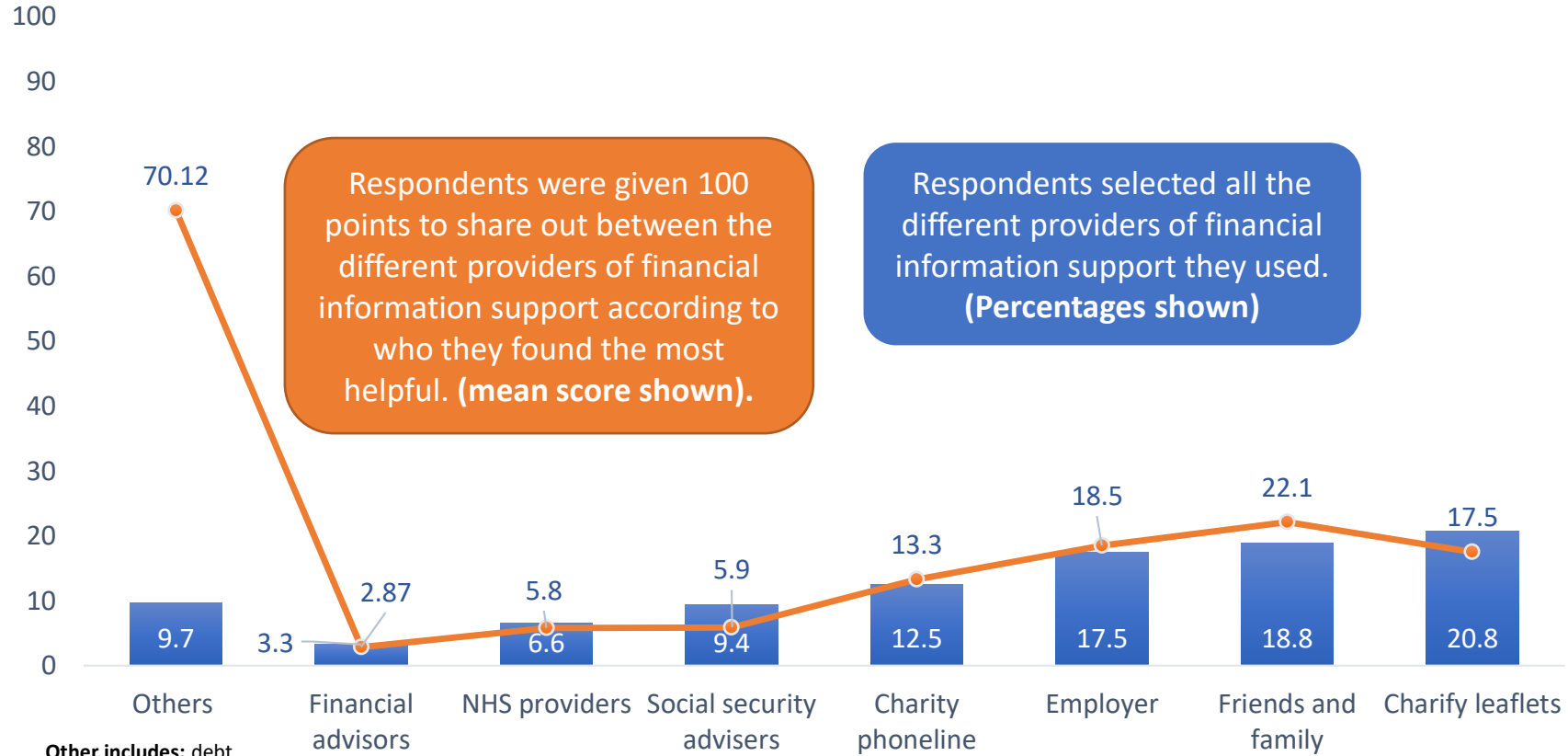
Medical information support



Financial Information Support Definition -

Information about available sources of financial support, information about managing employment, information about budgeting

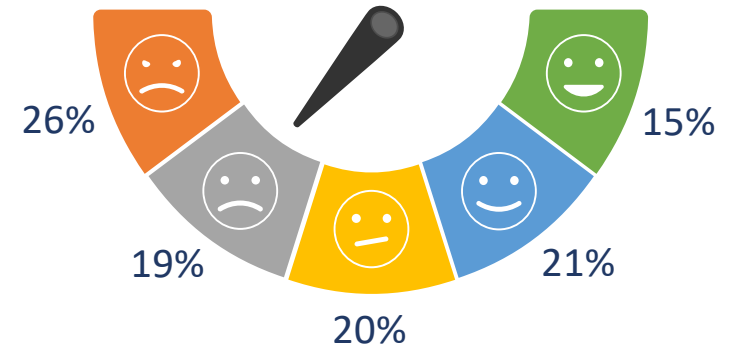
Financial information support



Respondents were given 100 points to share out between the different providers of financial information support according to who they found the most helpful. (mean score shown).

Respondents selected all the different providers of financial information support they used. (Percentages shown)

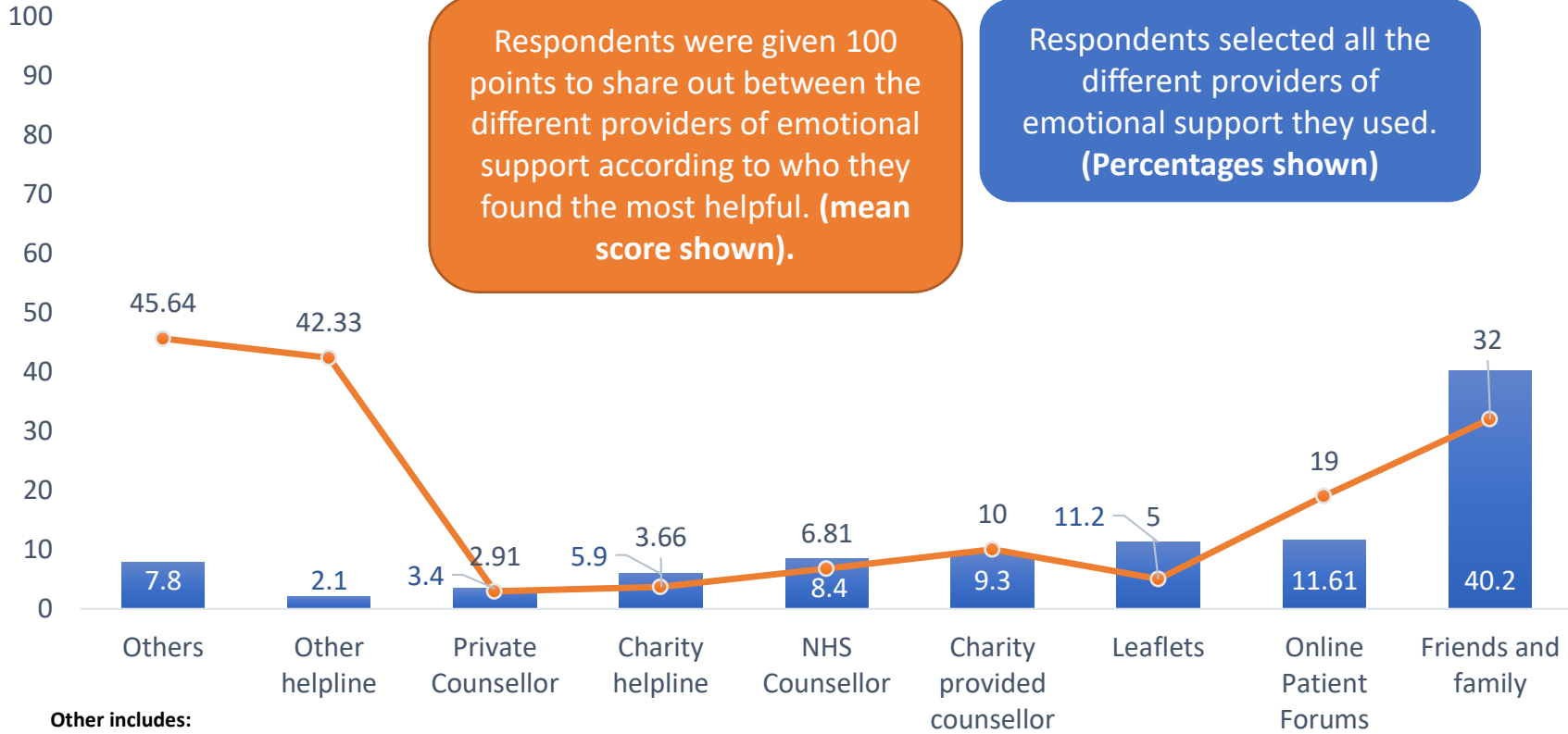
Respondent rating of the level of financial information support they received whilst under treatment?



Other includes: debt advisors, Macmillan financial advisors, Macmillan and cancer speciality nurses

Emotional Support Definition - help with depression, anxiety, fear about diagnosis, stress

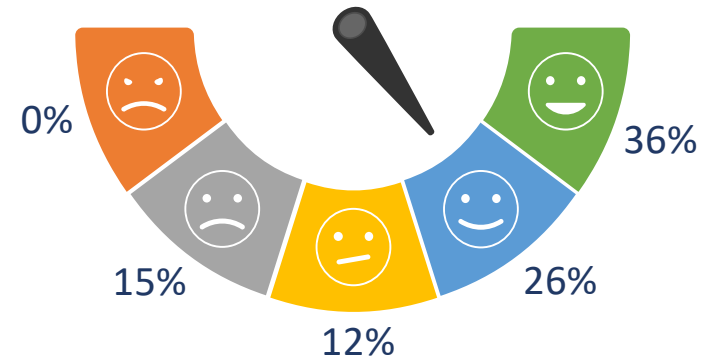
Emotional support



Respondents were given 100 points to share out between the different providers of emotional support according to who they found the most helpful. **(mean score shown).**

Respondents selected all the different providers of emotional support they used. **(Percentages shown)**

Respondent rating of the level of emotional support they received whilst under treatment?

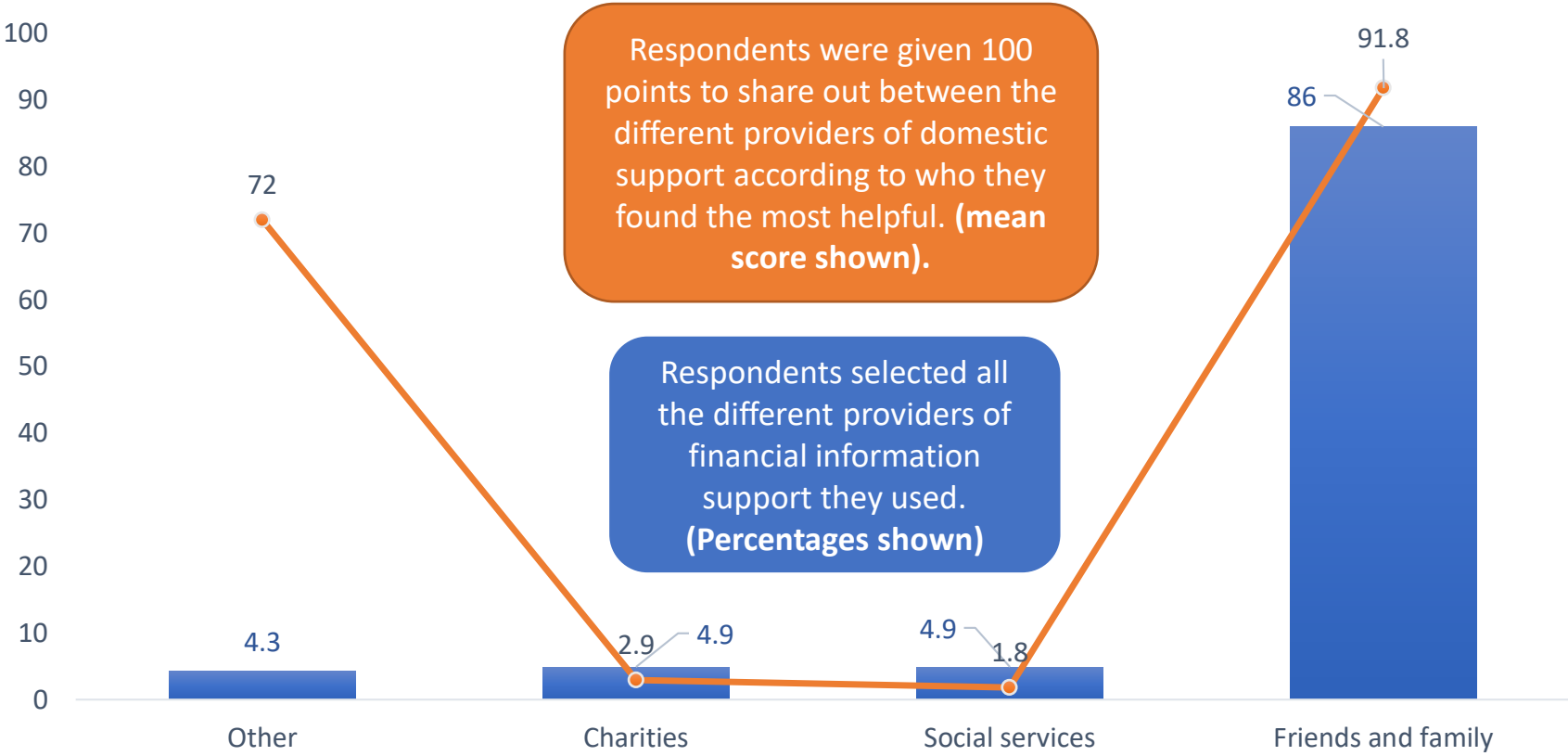


Other includes:

Psychologists, specialist nurses, other patients, hospice workers, support groups, social workers

Domestic Support Definition - help with sourcing medical aids for things like mobility or continence, support with childcare, pet-care, managing shopping

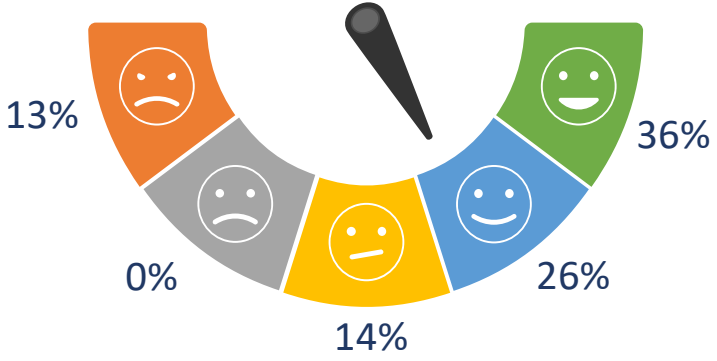
Domestic support



Respondents were given 100 points to share out between the different providers of domestic support according to who they found the most helpful. (mean score shown).

Respondents selected all the different providers of financial information support they used. (Percentages shown)

Respondent rating of the level of domestic support they received whilst under treatment?

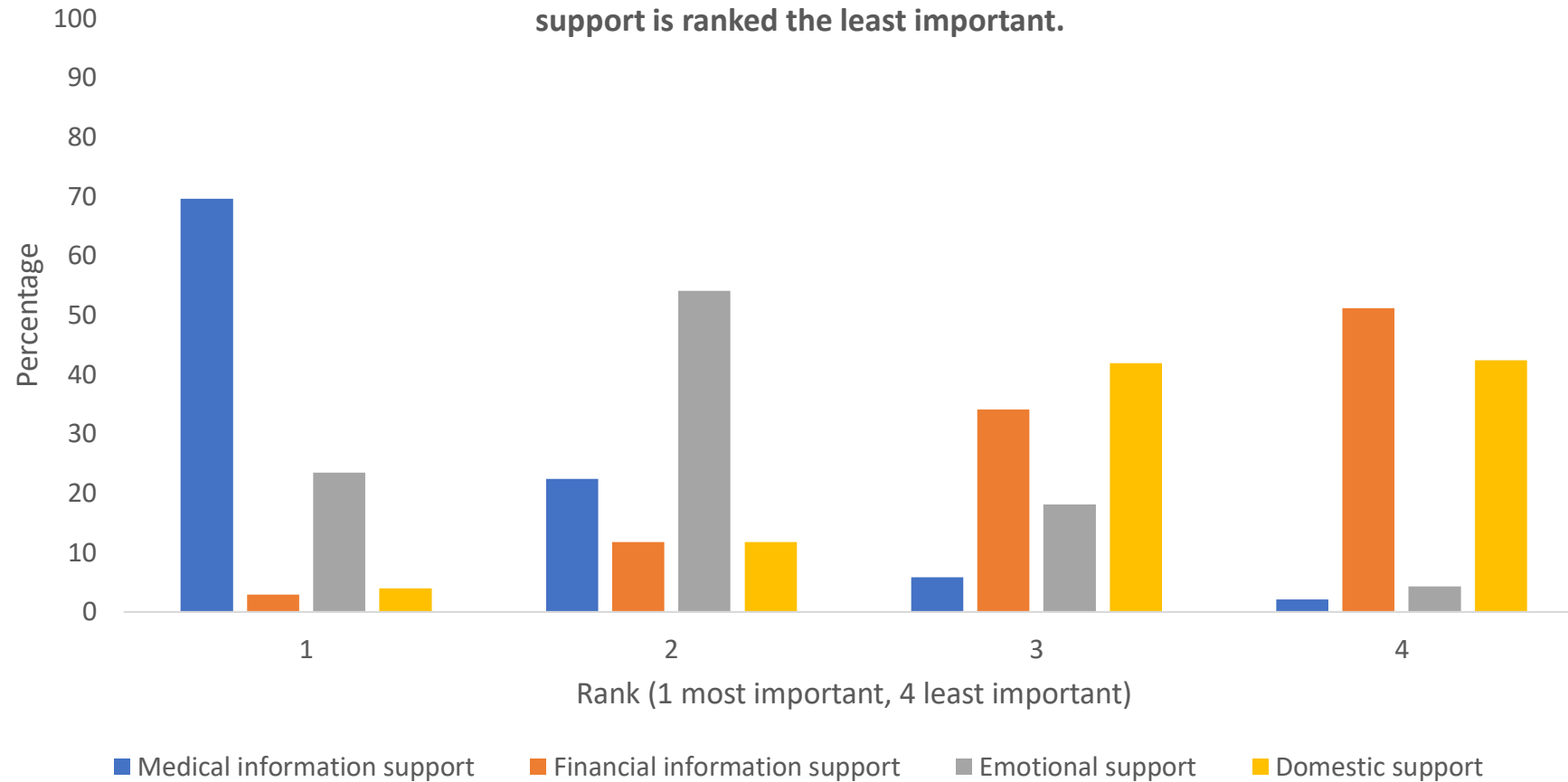


Other includes: Occupational therapy, district nurses, palliative care

N=413

Ratings for different types of support

When asked to rank the different types of support provided by importance - medical information was ranked as the most important type of support, followed by emotional support. Financial information support is ranked the least important.





Therapy adherence

- **Nearly a fifth** of respondents (19.75%) **sometimes fail to take their prescribed medicines because of the side effects**, with 1.57% doing this most of the time
- **Nearly 5%** of respondents **have not attended hospital for chemotherapy / radiotherapy sessions**, with 0.31% doing this most of the time.
- **More than 10%** of respondents **have used alternative medicines instead of those suggested by their doctors**; 31.67% have used alternative medicines alongside their prescribed treatment.



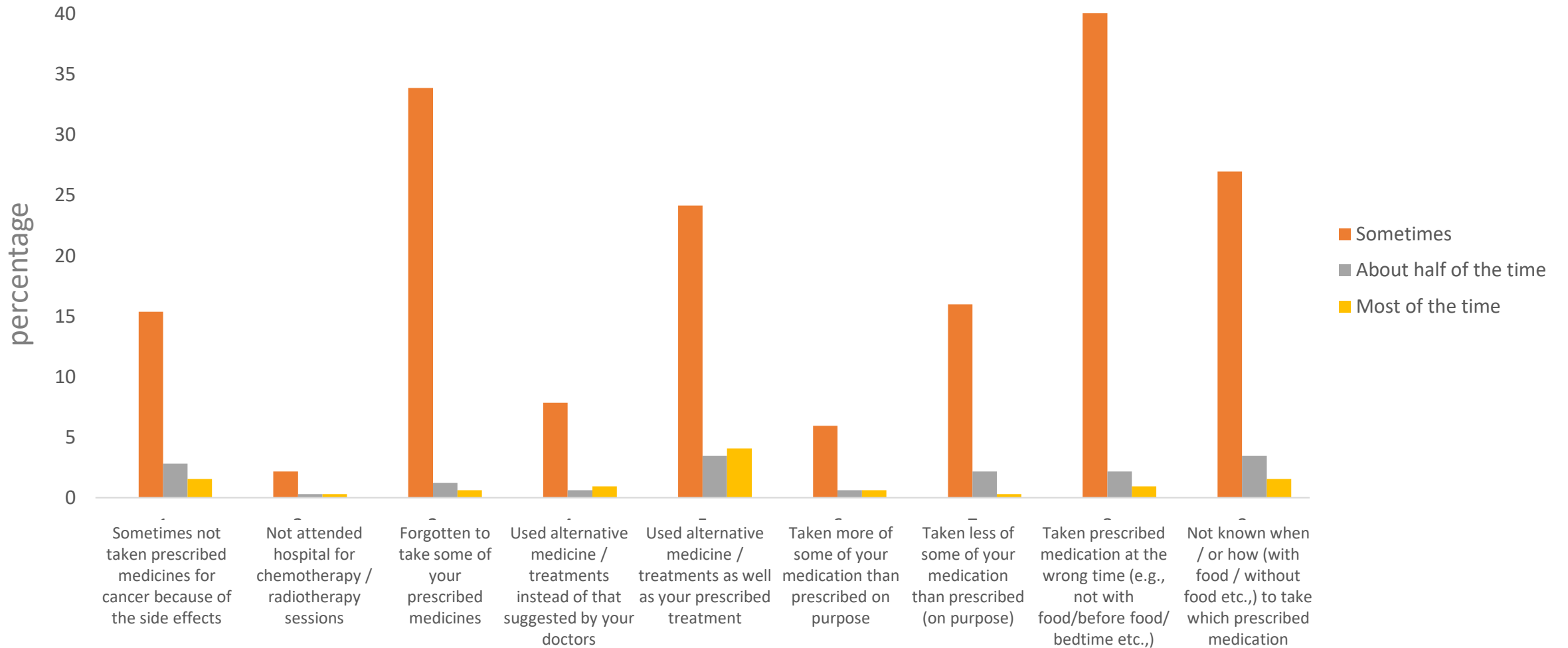
- **More than 7%** of respondents **have taken more of their prescribed medicine on purpose**, with 0.63% doing this most of the time.
- **Nearly a fifth (18.49%)** of respondents **have taken less of their prescribed dosage on purpose**; 2.5% do this about half the time or most of the time.
- **Nearly half of respondents (44.2%)** **have taken their medication at the wrong time**, with 3.13% doing this about half or most of the time.
- **A third of respondents (31.98%)** **have not known when or how to take their prescribed medication**, with 1.57% doing this most of the time.



Therapy adherence

	Sometimes not taken prescribed medicines for cancer because of the side effects	Not attended hospital for chemotherapy / radiotherapy sessions	Forgotten to take some of your prescribed medicines	Used alternative medicine / treatments instead of that suggested by your doctors	Used alternative medicine / treatments as well as your prescribed treatment	Taken more of some of your medication than prescribed on purpose	Taken less of some of your medication than prescribed (on purpose)	Taken prescribed medication at the wrong time (e.g., not with food/before food/bedtime etc.,)	Not known when / or how (with food / without food etc.,) to take which prescribed medication
Most of the time	1.57%	0.31%	0.63%	0.94%	4.08%	0.63%	0.31%	0.94%	1.57%
About half of the time	2.82%	0.31%	1.25%	0.63%	3.45%	0.63%	2.19%	2.19%	3.45%
Sometimes	15.36%	2.19%	33.86%	7.84%	24.14%	5.96%	15.99%	41.07%	26.96%
Never	78.37%	95.92%	63.95%	89.34%	63.32%	92.48%	80.25%	54.86%	67.71%

Therapy non-adherence





How much do the following effects of treatment matter?

Extending survival and quality of life are the most valued effects of treatment

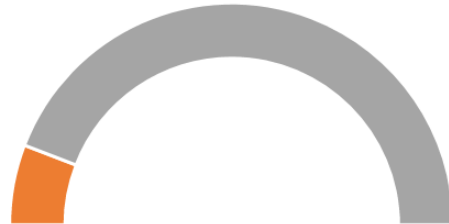
Respondents were given 100 points to share out between the different effects of treatment according to which was mattered most to them. (mean score shown).

Extending the overall length of my survival



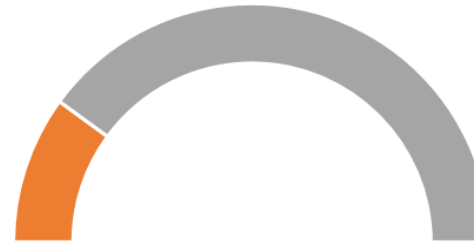
56.7 points

Extending the amount of time before my tumour progresses (grows) or spreads



21.1 points

Allowing me to maintain a reasonable quality of life



36.1 points

Shrinking the physical size of the tumour



21.1 points

Messages for health care providers and charities who support cancer patients?

“ Given the limited finance and understaffing situation in the NHS they do an Amazing job and I thank them all so much for providing such a great level of care.

It would have been intolerable without your care. I just don't have words to thank you all enough.

I cannot give enough praise and thanks for the wonderful work and support these groups do

The overwhelming message – more than a third of the comments - was one of gratitude for the support received:



Without their support, cancer can put you in a very lonely scary space.

They are brilliant, the support they give is second to none.

Cancer is a scary place. Thank you for making my journey easier.

You do an incredible job working in what can only be described as a very challenging and often upsetting role, but your worth is priceless.

”

BUT...

Messages for health care providers and charities who support cancer patients?

More than a *third* of the comments related to poor information, communication and anonymization

INFORMATION:

- Information at the time of diagnosis is **hard to take in**
- **Checklists** for patients about the stages of treatment **would be useful**
- **Printed information** as well as verbal
- Access to information varies widely across healthcare trusts, departments and bodies
- A broader more holistic offering of information including – where to access financial, emotional and domestic support

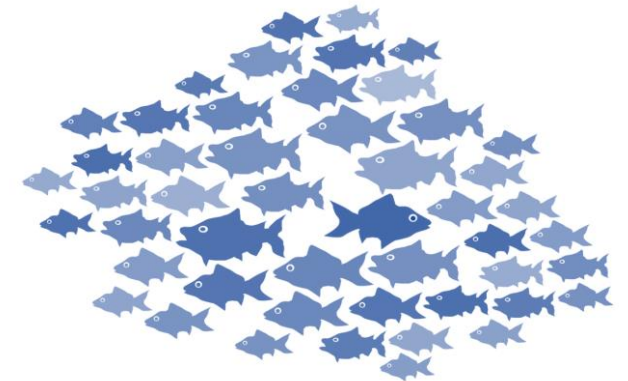


ANONIMIZATION:

- **Treat people as individuals** and don't 'anonymize' them
- A 'one size fits all' approach does not work
- People should be credited with intelligence and **given all the facts**
- Patronizing and 'talking down to' does not help patients

COMMUNICATION:

- Be honest: many comments stated that healthcare providers had **lacked transparency**
- **Listen**
- Don't try to 'sugar coat' diagnosis, prognosis or implications of treatment
- **Make side effects more clear**
- **Reduce waiting times for results**
- **Communicate at an appropriate level for the patient** – not 'one size fits all' approach





Messages for health care providers and charities who support cancer patients?



*This is your job & sometimes you can be blasé. **It was all new to me & terrifying.** More information & help should be offered **& we shouldn't have to try & find things out for ourselves** such as **financial help & benefits**. I got the most help from CAB who told me about the MacMillan grant & put me in touch with Perennial Trust & Retail Trust & paid towards my gas & electric. I received excellent treatment but **once it's finished you feel confused & abandoned...**"is that it? what happens next".*

*Please look at the **whole person, not just your specialty**. We have issues with side effects and often **do not know whether a symptom or pain is caused by the treatment, the cancer or something additional**. Help us through this and not make us feel that we are just being paranoid. It is a very difficult road to travel, so please **don't make us feel bad for being frightened or for asking too many questions**. We rely on your expertise, but it is our body and our lives.*

*We as patients are not sure what we need to ask, a **list of possible or frequently asked questions would be useful***

*More information on chemo - **check lists for patients** including more information on side effects and ways to mitigate*

***Don't assume** patients know what your talking about. Some people don't want to know all the details but I think **patients should be asked** if they do want to know the full details.*

*Remember we are a person first and patient second. **Treat us individually and holistically.***

*You're used to this, the terminology and jargon, we aren't. **Use plain English to explain what is happening.** Leaflets are all very well but the initial shock of receiving a cancer diagnosis, no matter what the stage and grading is, is overwhelming. Trying to read a leaflet can be pretty hopeless, **a voice might have more impact***

*Please speak in **plain English** and don't assume that we know what you are talking about.*

*Have **more information available about rarer cancers**; better financial advice and offer more support to family members.*

***Give more information.** Ask if there is more information we would like and spend time talking to us. I felt there were huge gaps in the information I was given and I rarely saw my oncologist*



LDA Research
International Medical Market Insights

Messages for health care providers and charities who support cancer patients?

More than a *fifth* of the comments related to lack of emotional or financial support, poor aftercare and a need for a more unified approach

EMOTIONAL AND FINANCIAL SUPPORT

- Information relating to access for emotional and financial support **varies widely**
- There is a **need for recognizing patients without a support network** from friends and family
- **Information** on financial benefits during treatment is **hard to access**
- There is an **overreliance on friends and family to offer emotional support**
- **Males find it particularly difficult** to access emotional support



AFTERCARE

- Give patients **information on what symptoms** might indicate **relapse** post treatment
- **Don't withdraw all support immediately** post treatment
- Emotional **support** should be offered to **cancer survivors**
- Be aware that **carers and family also need support**, not just the patient themselves

UNIFIED APPROACH:

- Treatments seem to differ a lot across and within healthcare trusts
- HCPs should **work together** and work alongside and promote charities too
- Levels of care should be nationwide and not **differ from hospital to hospital**





Messages for health care providers and charities who support cancer patients?

“ Thank you for getting me through a very difficult time. I hope I never have to use your services again but if I do, **I would like more aftercare support.** I felt left alone and frightened for my future when my treatment finished.

Please provide emotional support **& somewhere to ask questions AFTER active treatment** has ended. Don't leave people in an emotional wilderness.

To understand the importance of emotional support. I felt like someone on a conveyor belt that needs to be rushed through.

It would be nice to have **more physical support** for those that consider themselves fit and healthy prior to diagnosis I.e. Exercise regimens appropriate for the treatment to maintain mobility, strength and boosting confidence/ motivation/ well being feeling

Financial struggle is as bad as the cancer.

Not enough support from anyone had to chase it all myself. It was left up to my husband to support me.

Support **varies by postcode** as does treatment and follow up.

This is your job & sometimes you can be blasé. **It was all new to me & terrifying.** More information & help should be offered **& we shouldn't have to try & find things out for ourselves** such as **financial help & benefits.** I got the most help from CAB who told me about the MacMillan grant & put me in touch with Perennial Trust & Retail Trust & paid towards my gas & electric. I received excellent treatment but **once it's finished you feel confused & abandoned...**"is that it? what happens next".

Focus more on emotional support ... sometimes you have to be more direct / pushy with patients, to ascertain if they need this type of support (especially with men) !!

Treatment and care during cancer was great. **Afterwards,** it is almost non-existent and **you feel very alone.**

Emotional support is important and quality of life is very important a plan of action would be appreciated. Reoccurrence is not covered enough or outlooks it feels dire. After initial treatment is finished the worry of reoccurrence is real follow ups should be regular

Recognise and address the **emotional impact cancer** diagnosis has. We are not just a set of physical symptoms.

Not enough support from anyone had to chase it all myself. Pay for private counselling. No financial help. It was left up to my husband to support me



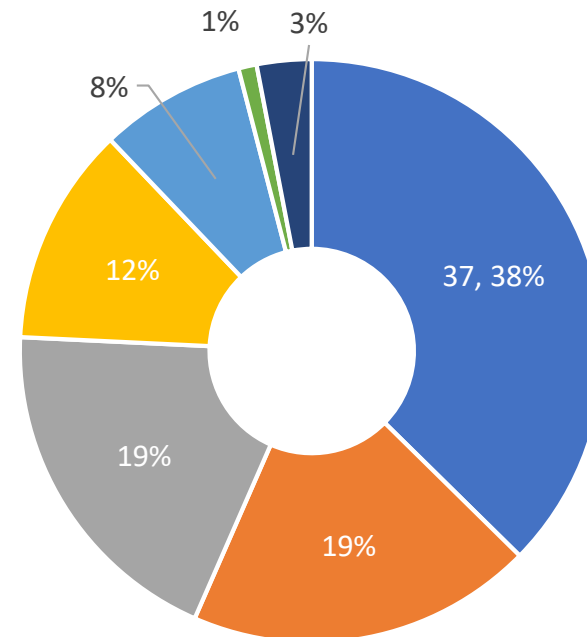


Messages for drug companies who manufacture treatments for cancer

Whilst again there was a sense of gratitude towards the drug companies, there was a much more diverse response to this question. There was an overwhelming sense that cancer treatment drugs are overpriced – almost two fifths of respondents – and nearly two fifths again supported more research into treatments and a reduction in side effects from the drugs:

Comments by frequency

- *High price*
- *More research being required*
- *Need for reduced side effects*
- *Gratitude*
- *Packaging, drug format and information*
- *Alternative natural remedies*
- *Other*





Messages for drug companies who manufacture treatments for cancer

“

Please, **please reduce your costs**, so Nice will authorise the use, far too many people are dying from a disease that you can live with, what is the point in raising funds for cancer research when patients are unable to access the drugs

Why can they not be made cheaper ? I don't understand why some people cannot have or continue to have a drug that works for them

Make your drugs cheaper so that ALL cancer patients can have them. I do believe that the drug that can eradicate cancer is out there but companies prefer to put their own financial gains before human life!!!!

Use plain English to **explain about side effects**. Give % of side effects so you can pick out which are really likely to happen. **Understand how cocktails of drugs interact with each other** - you are seldom taking just one medication. I found it particularly tiresome having to take medication to manage the side effects of the medication that was managing the side effects of the chemo!!

Please take note of and **encourage patients to report side effects**. They are debilitating for the patient and for their family. It is not just survival at any cost. Even different brands of the same drug can have different side effects.

Really unbelievable how can they expect people to take some drugs are so **awful tasting** how can it be so hard. To sort this problem

Make sure the drugs are always available, i.e. Tamoxifen. There have been occasions that my pharmacist has not been able to get any, and regularly can't get the specific brand which gives me the least side-effects.

Please **be very honest about the side effects** of treatment. Employ more clinical pharmacists to identify contra indications of **side effects from multiple medication**

”



Messages for drug companies who manufacture treatments for cancer

“

If your doctor suggest you take your medication at a **certain time** to **make this clear** to us as we are not also remembering what the doctors says.

Make the **packaging easier to open**; indicate days of the week on packaging (I used to forget if I'd taken the tablets)

Clearer guidance on side effects, the 1 in 1000 or 20 in 1000 affected doesn't really help!!!

Make information in **easier language** to understand

Better instructions on medication

Tastier so people don't dread taking it

Explain side effects with **common language** and truthfully not medical jargon

Make sure the packaging the tablets come in are **easy to open** when you have no energy/strength

Make more **liquid form or injection or patches**

I would have liked an **individualised information pack** giving all drug information, s/e's and their management all in one pack. Maybe the drug companies could work with the HCPs to produce this.

”

Thank you



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