



National Cancer Patient Experience Survey 2022

National Results Webinar

CPES@PickerEurope.ac.uk

#pickerworkshops #cpes22



Agenda



Listening to Patient Voices

Sara Turle (Patient Partner)



The National Perspective

Jodie Moffat (Deputy Director of Policy and Strategy)



Key Findings

Caroline Hancock (Research Associate, Picker)



What do we think?

Clare Lerway (Senior Insight Associate, Picker)



Royal Free London: Cancer Improvement Collaborative

Azmina Rose (Lead for Cancer Patient Experience & Macmillan Centres)

Kerry Guile (Consultant Nurse Oncology and Co-Clinical Director NCL SACT ERG)



Closing remarks

Neil Churchill (Director for Experience, Participation and Equalities, NHS England)

Objectives



Understand the national picture



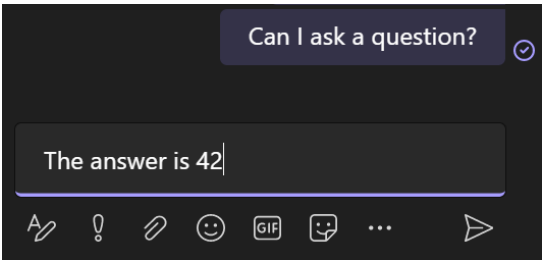
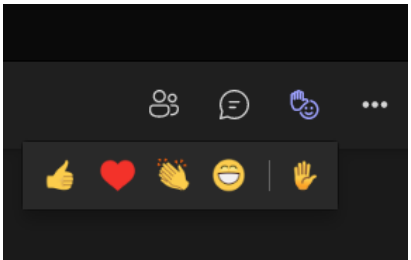
To celebrate areas of success in cancer care



To share improvement learning and experiences



Answer your questions





Listening to Patient Voices

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(Patient Partner)

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The National Perspective

Jodie Moffat

(Deputy Director of Policy and Strategy, NHS England)

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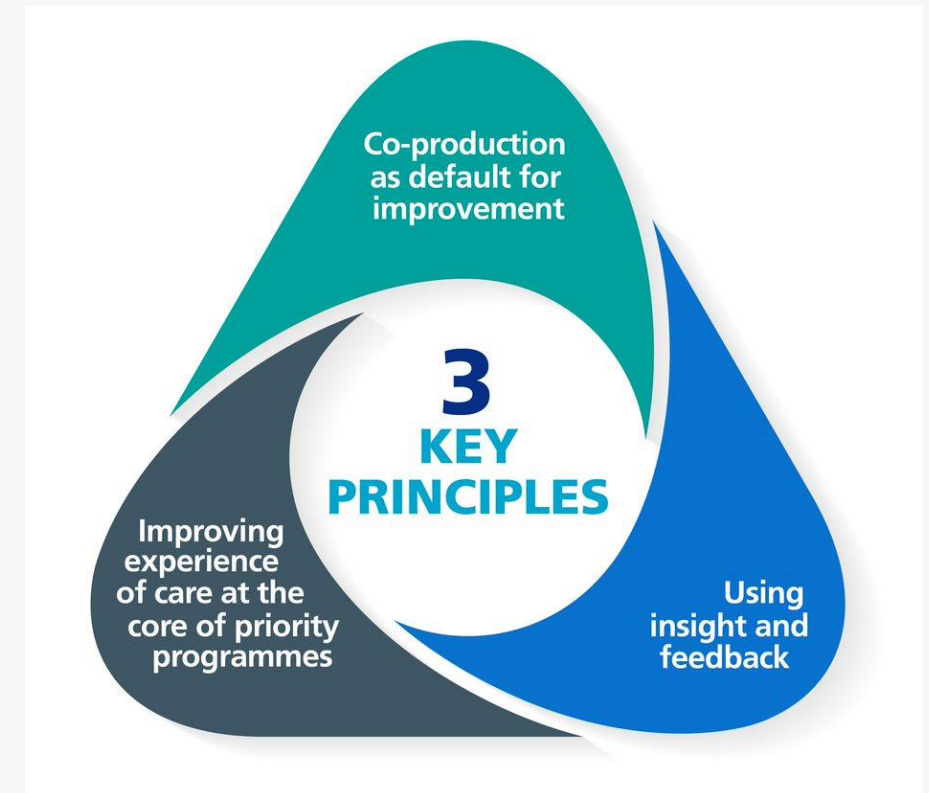


A Shared Understanding of Experience of Care

The **experience** that a person has of their care, treatment and support is **one of three parts of high-quality care**, alongside clinical effectiveness and safety



There are 3 **key principles** that should always be considered when planning for the delivery of best possible experience



[NHS England » Improving experience of care: A shared commitment for those working in health and care systems](#)

Priorities for the NHS Cancer Programme

Diagnose cancer earlier and improve survival

Improve patient experience and quality of life

Speed up cancer pathways and improve operational performance

Reduce health inequalities in cancer services



Patient feedback is vital to improve experience during cancer diagnosis, treatment and follow up

CPES – the National Cancer Patient Experience Survey – is one part of the picture

- Provides a valuable national view which supports various breakdowns
- Is a useful source of local insight that can be considered alongside other sources of insight



How do we use it as a team?

CPES informs where we focus attention

We've used CPES and under 16 CPES results to inform the focus of our Cancer Experience of Care Improvement Collaborative

The Collaborative brings together different cancer healthcare professionals and people with lived experience to use insight and feedback to improve experiences of care

What are we trying to accomplish?

How will we know that a change is an improvement?

What changes can we make that will result in improvement?



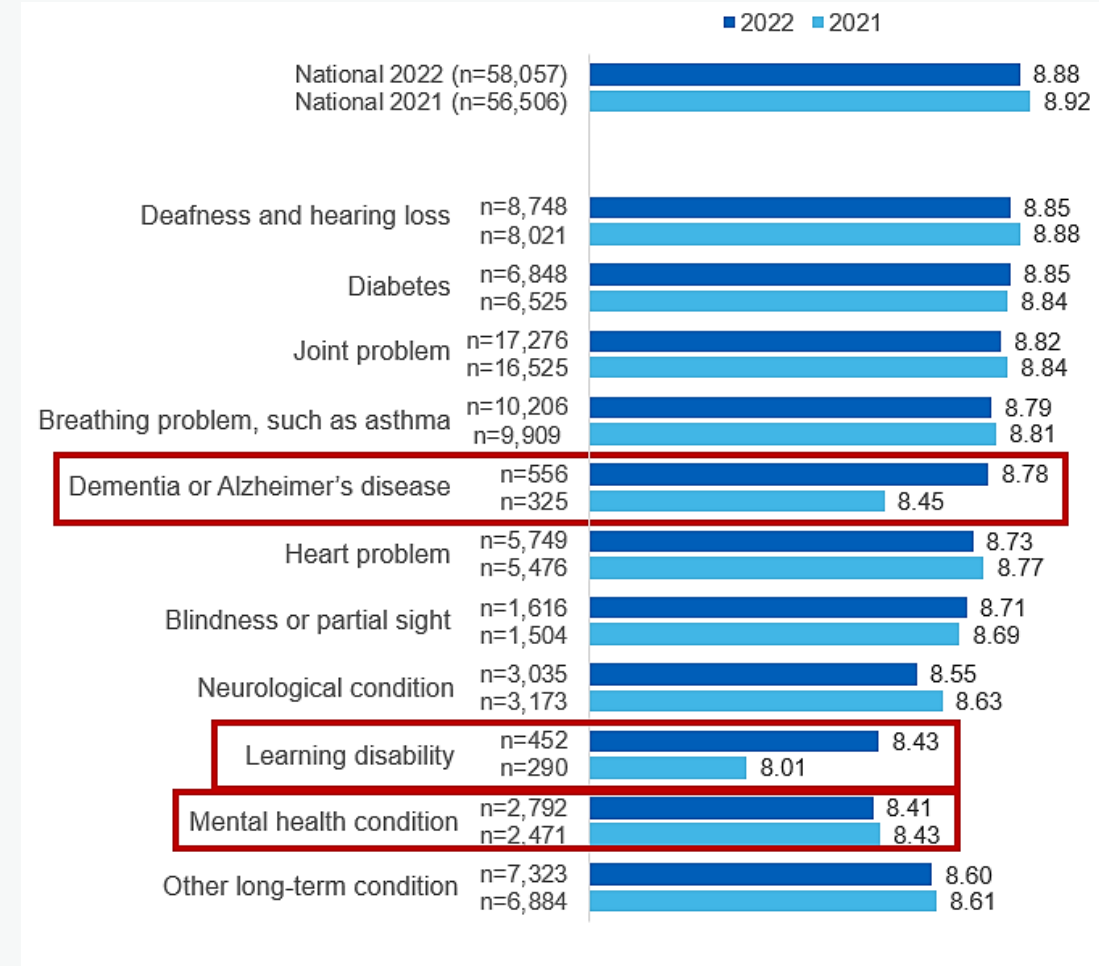
We have recently invited expressions of interest to our 5th CIC cohort

CPES results reveal that people with a pre-existing condition tend to report a lower overall experience of care

Cohort 5 is focusing on driving improvements for people with pre-existing conditions:

- Mental health
- Learning Disability & Autism
- Dementia
- Any pre-existing condition

Cohort 5 is launching in September and will run until Spring 2024.



Overall experience by long term condition (Q59)

Identifying and celebrating innovation and good practice

Cancer Experience of Care Award

In partnership with the Patient Experience Network the purpose of this category is to recognise and promote the use of data and/or other insight (including CPES) to drive and deliver measurable improvements in patient experience

This category is free to enter due to NHSE and Macmillan Cancer Support sponsorship





Key Findings

Caroline Hancock

(Research Associate, Picker)

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Key sources of data for CPES22

National Reports

- Quantitative overview of national results (standard)
- Quantitative overview of national results (Easy Read version)
- Infographic
- National level data tables – Excel

Alliance Reports

- Cancer Alliance Level Reports – PDF – Quantitative
- Cancer Alliance data tables – Excel

ICB Reports

- ICB Reports – PDF – Quantitative
- ICB data tables – Excel

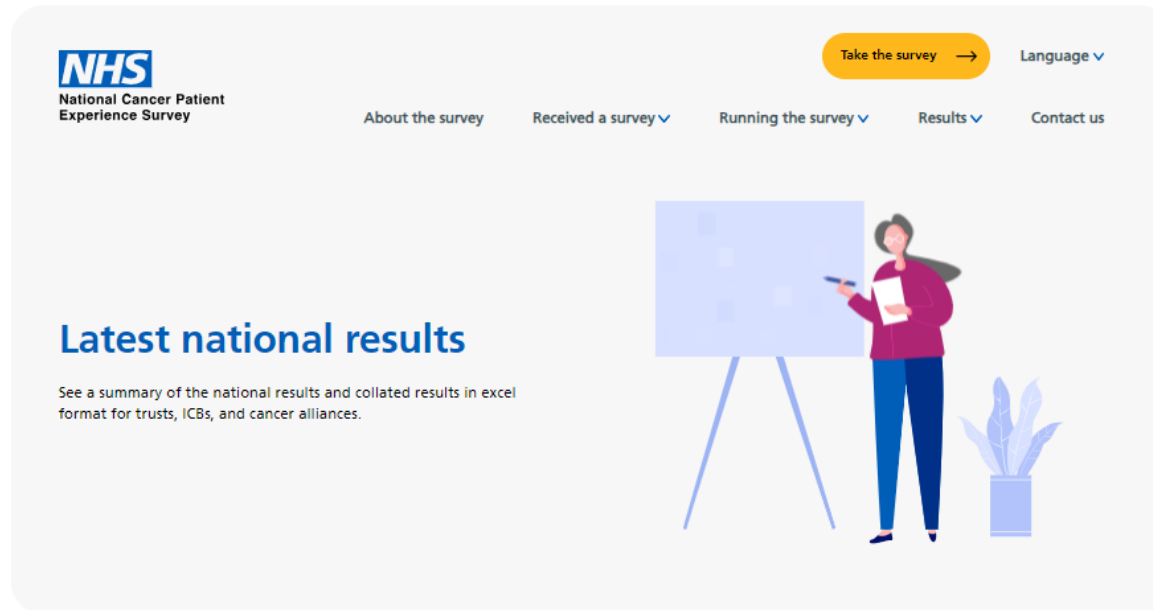
Trust Reports

- Trust Reports – PDF – Quantitative
- Trust data tables – Excel
- Free text workbooks - Excel

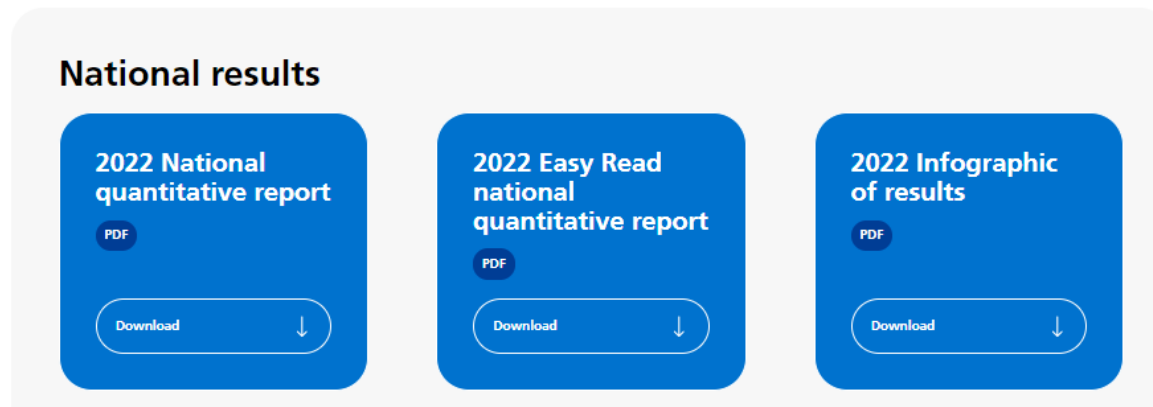
Delve deeper using the new interactive reporting tool
www.ncpes.co.uk/interactive-results/

Visit the CPES website to find results...

<https://www.ncpes.co.uk/results-2022/>



The screenshot shows the top navigation bar of the NHS National Cancer Patient Experience Survey website. It includes the NHS logo, a 'Take the survey' button, and a language dropdown menu. The main navigation menu contains links for 'About the survey', 'Received a survey', 'Running the survey', 'Results', and 'Contact us'. The central content area features an illustration of a person presenting at a whiteboard, with the heading 'Latest national results' and a sub-heading 'See a summary of the national results and collated results in excel format for trusts, ICBs, and cancer alliances.'



The screenshot shows the 'National results' section of the website. It features three blue buttons, each representing a different report available for download. Each button includes a 'PDF' icon and a 'Download' button with a downward arrow.

Report Title	Format	Action
2022 National quantitative report	PDF	Download
2022 Easy Read national quantitative report	PDF	Download
2022 Infographic of results	PDF	Download

New dashboard

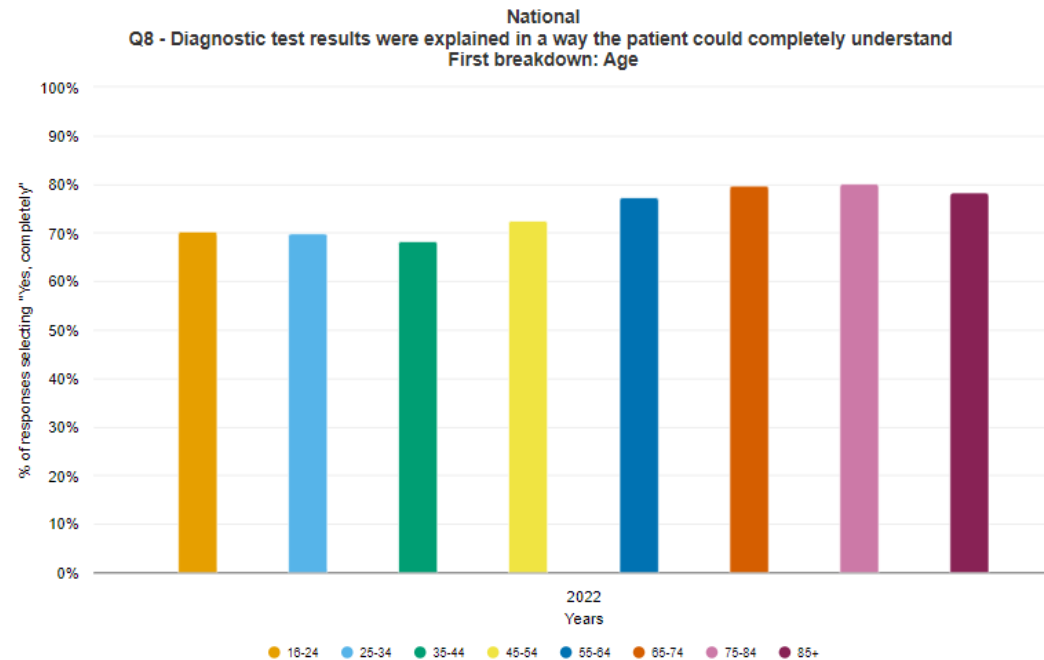
<https://www.ncpes.co.uk/interactive-results/>

National Cancer Patient Experience Survey

Questionnaire section	Question	Year
14 items selected	Q8 - Were the results of the tests explained	2022
Choose your first breakdown	Filter your first breakdown	
Age	8 items selected	
Choose your second breakdown	Filter your second breakdown	
No breakdown selected	Nothing selected	

Scores

Frequencies



New infographic



National Cancer Patient Experience Survey 2022

53% response rate

61,268 people responded

59%

said the possible long-term side effects, including the impact on their day-to-day activities, were definitely understood

62.4%

said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns



8.88

On a scale of 0 (very poor) to 10 (very good), the average rating of care was 8.88



86.7%

said the administration of their care was very good or good



75.9%

said they had been given the option of having a family member, carer or friend with them when they were first told they had cancer

91.5%

said they had a main contact person who would support them through treatment within the team looking after them

71.1%

said that before their treatment started, they had a discussion about their needs or concerns with a member of the team looking after them



44.7%

said they got the right amount of support from staff at their GP practice during treatment

65.4%

of people who had contacted their GP practice said that the referral for diagnosis was easy to understand



78.6%

who had an overnight stay said they had confidence and trust in all of the team looking after them



Visit ncpes.co.uk to see detailed national, Cancer Alliance, ICB, and NHS Trust results

The interactive reporting tool available [here](#), allows you to explore the survey in more detail

A national report is available setting out the headline findings



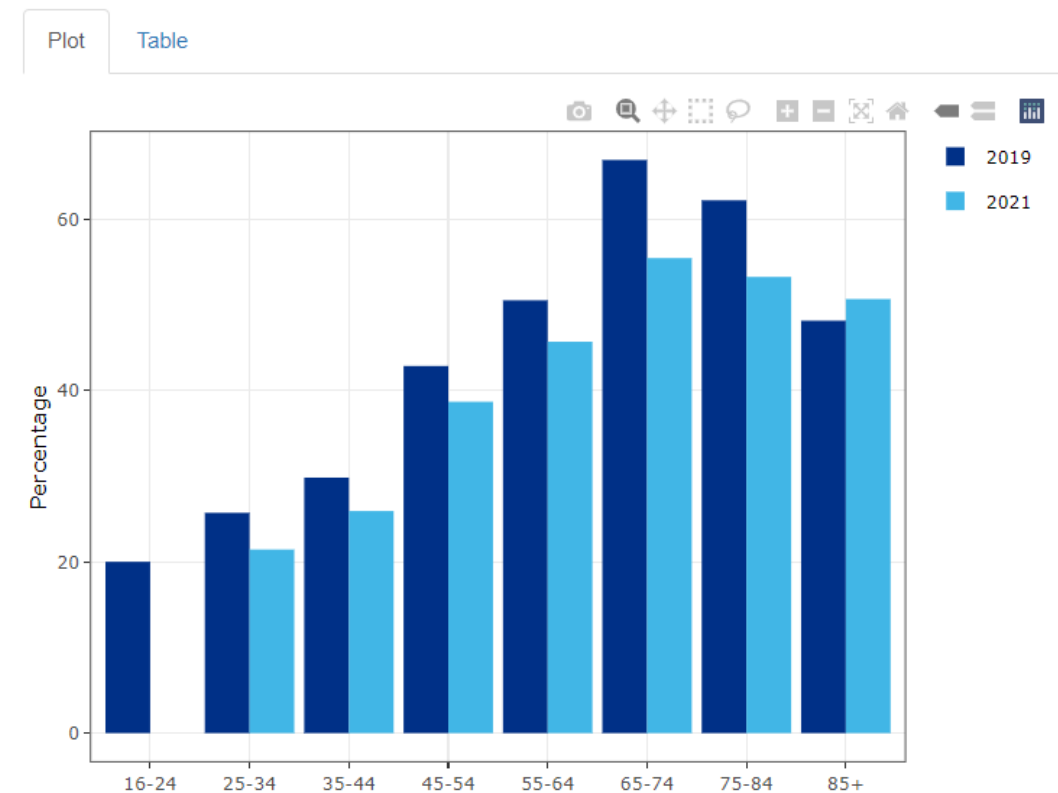
Coming soon... response rate analysis

- Provided at national and trust level, data on the response rates of different population groups. This helps us to understand how well the responses collected reflect the make-up of the eligible population, and see whose voices are being missed.

- Response rates will be provided by:

- Age
- Deprivation
- Ethnicity
- Tumour group
- Cancer type

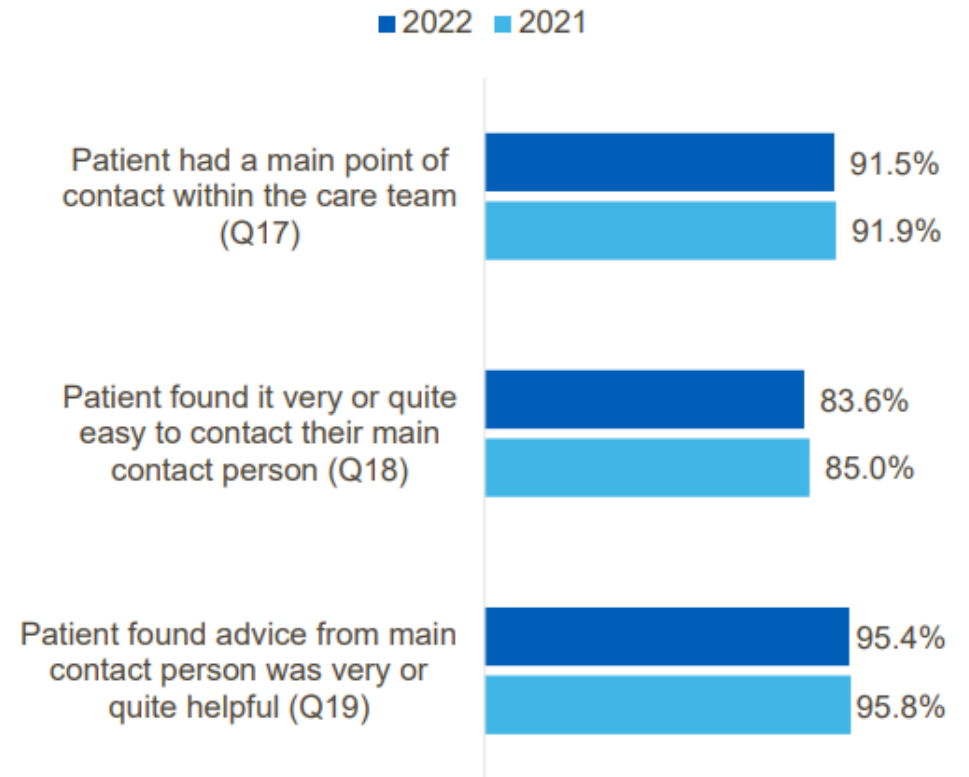
Response rates by age group



New for 2022 – Trend Data

- The CPES Advisory Group oversaw review of the questionnaire for CPES 2021
- The survey now reflects the significant changes in service delivery, clinical practice and policy that have been made
- Year on year comparisons between 2021 and 2022 are included in reporting

Year on year comparisons for questions about support from a main contact person at hospital



Sub-group Comparisons

Comparing the overall experience by sub-group allows us to explore the differences in how people experienced their cancer care.

The following subgroup breakdowns are available to explore:

- Age
- Male/Female/Non-binary/Other
- Sex registered at birth
- Sexual orientation
- Long-term condition
- Ethnicity
- IMD quintile
- Cancer outcome
- Cancer spread to other parts of the body
- Tumour group



Eligibility and who we heard from



CPES – who is eligible

- All acute and speciality NHS Trusts in England that provide adult cancer services
 - Adults > 16 years
 - Confirmed primary diagnosis of cancer

Adults who were:

- EITHER: Admitted to hospital as an inpatient
 - OR: a day case patient
 - For cancer related treatment
- Discharged between **1 April 2022 and 30th June 2022**



Respondents

- Response rate of **53%**

61,268 out of **115,662** patients surveyed responded

Number of responses by Male/Female/Non-binary/Other

	No. of responses	% of responses
Female	31,638	51.6%
Male	26,402	43.1%
Non-binary	13	0.0%
Prefer to self-describe	13	0.0%
Prefer not to say	83	0.1%
Not given	3,119	5.1%
Total	61,268	100.0%

Number of responses by age

Age	No. of responses	% of responses
16-24	148	0.2%
25-34	508	0.8%
35-44	1,731	2.8%
45-54	5,058	8.3%
55-64	13,162	21.5%
65-74	21,078	34.4%
75-84	16,785	27.4%
85+	2,798	4.6%
Total	61,268	100.0%

Respondents

Number of responses by long-term condition

Long-term condition	No. of responses	% of responses
Joint problem, such as arthritis	18,235	29.8%
Breathing problem, such as asthma	10,795	17.6%
Deafness or hearing loss	9,228	15.1%
Diabetes	7,251	11.8%
Heart problem, such as angina	6,098	10.0%
Neurological condition	3,177	5.2%
Mental health condition	2,936	4.8%
Blindness or partial sight	1,722	2.8%
Dementia or Alzheimer's disease	592	1.0%
Learning disability	496	0.8%
Other long-term condition	7,655	12.5%

Number of responses by tumour group

Tumour group	No. of responses	% of responses
Breast	14,023	22.9%
Haematological	8,636	14.1%
Colorectal / LGT	7,500	12.2%
Prostate	6,346	10.4%
Urological	4,544	7.4%
Lung	3,957	6.5%
Gynaecological	2,828	4.6%
Upper gastro	2,808	4.6%
Skin	2,301	3.8%
Head and Neck	1,627	2.7%
Sarcoma	507	0.8%
Brain / CNS	227	0.4%
Other	5,964	9.7%
Total	61,268	100.0%

Scores with the largest negative change and scores with the largest positive change



The five scores with the largest negative change

Question	2021	2022	Change
Q34 - Patient was always able to get help from ward staff when needed	76.2%	72.5%	-3.7%
Q07 - Patient felt the length of time waiting for diagnostic test results was about right	81.9%	78.4%	-3.5%
Q35 - Patient was always able to discuss worries and fears with hospital staff	66.8%	64.2%	-2.7%
Q31 - Patient had confidence and trust in all of the team looking after them during their stay in hospital	80.9%	78.5%	-2.3%
Q29 - Patient was offered information about how to get financial help or benefits	69.5%	67.5%	-2.0%

The five scores with the largest positive change

Question	2021	2022	Change
Q12 - Patient was told they could have a family member, carer or friend with them when told diagnosis	70.1%	75.9%	+5.8%
Q22 - Family and/or carers were definitely involved as much as the patient wanted them to be in decisions about treatment options	74.7%	80.0%	+5.3%
Q32 - Patient's family, or someone close, was definitely able to talk to a member of the team looking after the patient in hospital	60.6%	65.6%	+5.0%
Q52 - Patient has had a review of cancer care by GP practice	18.0%	20.7%	+2.7%
Q49 - Care team gave family, or someone close, all the information needed to help care for the patient at home	55.4%	57.9%	+2.6%

Headline Findings (Quantitative)



Overall experience



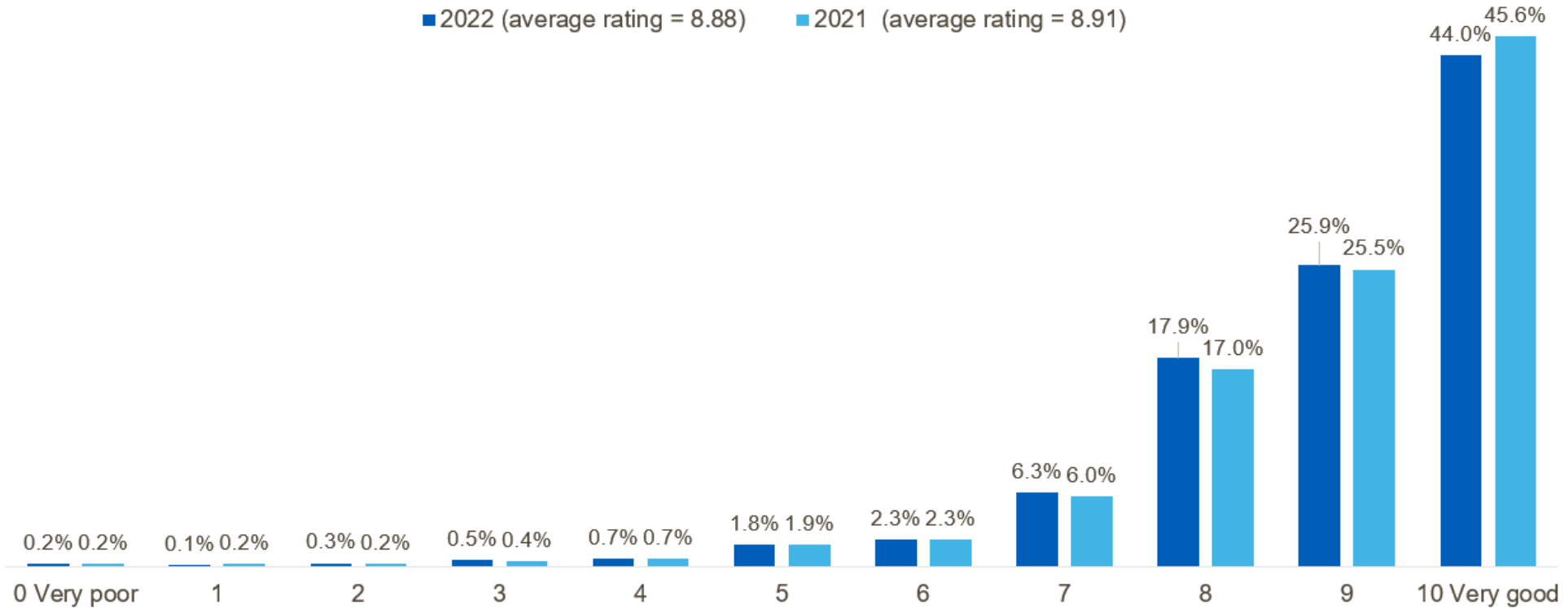
Overall experience

8.88

Respondents' average rating of care scored from very poor to very good (scale from 0 to 10) (**8.91** in 2021).

Year on year comparisons* for Q59 'Overall, how would you rate your care? (scale from 0 to 10)'

■ 2022 (average rating = 8.88) ■ 2021 (average rating = 8.91)



Diagnostic tests and finding out that you had cancer



Diagnostic tests

78.3%

said that the results of diagnostic tests were explained to them in a way they could completely understand (**78.7%** in 2021).



Finding out that you had cancer

75.9%

said that when they were first told that they had cancer, they had been given the option of having a family member, carer or friend with them (**70.1%** in 2021).

Finding out that you had Cancer

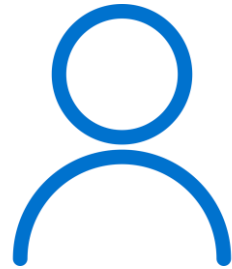
Just over three-quarters of all respondents (**76%**) said that when they were first told that they had cancer, they had been given the option of having a family member, carer or friend with them. This is an increase from 70% in 2021.

When asked how they felt about the way they were told they had cancer, **74%** said they were told sensitively. Overall, **85%** (up from 84% in 2021) said that they were definitely told about their diagnosis in a place that was appropriate for them.

76% (compared with 77% in 2021) said their cancer diagnosis was explained in a way they could completely understand. **84%** (up from 83% in 2021) said they were told they could go back later for more information about their diagnosis after they had had time to reflect on what it meant.



Support from a main contact person and care planning



Support from a main contact person

91.5%

said they had a main contact person within the team looking after them who would support them through treatment (**91.9%** in 2021).



Care planning

71.1%

said that before their treatment started, they had a discussion with a member of the team looking after them about their needs or concerns (**71.7%** in 2021).

Support from a main contact person

Nine out of ten respondents (92%) said they had a main contact person within the team looking after them who would support them through treatment. This score compares with 92% in 2021.

Of these respondents, **84%** said it was 'very' or 'quite easy' to contact their main contact person, a decrease from 85% in 2021.

And **95%** (down from 96% in 2021) said that they found the advice from their main contact person to be 'very' or 'quite helpful'.



Care Planning

Respondents were asked questions about how they were supported during their cancer care.

71% (72% in 2021) said that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns.

Of those who had a discussion about needs and concerns, **93%** (93% in 2021) said that their care team had helped them to create a care plan to address these.

99% said a member of the team looking after them reviewed the plan with them to make sure it continued to reflect their needs or concerns. This is unchanged from the 99% of respondents in 2021.



Hospital care and care from your GP practice



Hospital care

78.5%

of respondents who had an overnight stay said they had confidence and trust in all of the team looking after them (**80.9%** in 2021).



Care from your GP practice

44.6%

of respondents who said their GP practice was involved in their care while they were having treatment said they got the right amount of support from staff at their practice (**43.7%** in 2021).

Hospital Care

88% of respondents felt that they were always treated with respect and dignity while they were in the hospital. This is down from 89% in 2021.

When asked 'Did the hospital staff do everything you wanted to help control your pain?', **84%** (down from 86% in 2021) of respondents said this was definitely the case.

88% of respondents felt they were given clear written information about what they should or should not do after leaving hospital and that this information was easy to understand, compared to 89% in 2021.

Respondents who had been treated as an outpatient or day case were asked if they were able to talk to hospital staff about their worries or fears if they needed to. **78%** said 'yes this was always the case'.



Hospital Care

However in some areas of hospital care respondents reported a more negative experience.

66% respondents who had stayed overnight said family or someone else close to them were definitely able to talk to someone on the team looking after them if they wanted to. This is an increase from 61% of respondents in 2021.

During their hospital stay, **64%** (down from 67% in 2021) of respondents said they could always talk to the hospital staff about their worries and fears if they needed to.

70% (70% in 2021) of respondents said they always felt involved in decisions about their care and treatment whilst in hospital.



Care from your GP Practice

Respondents were asked if they got the right amount of support from staff at their GP practice while they were having cancer treatment. Of those that said their GP practice was involved in their cancer treatment, **45%** said this was definitely the case. This compares with 44% in 2021.

21% of all respondents said they had a review of their cancer care by a member of staff at their GP practice. This is up from the 18% seen in 2021.



Living with and beyond cancer



**Living with and beyond
cancer**

62.4%

said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns (**62.5%** in 2021).

Living with and beyond cancer

Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services. **31%** of respondents that needed care and support said this was definitely the case. This score compares with 32% in 2021.

78% said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns. This score is unchanged from 2021.



Further Guidance

For guidance on scoring, suppression and how to use the reports please refer to the Technical Document on the CPES website

<https://www.ncpes.co.uk/survey-instructions/>

Or email the team:

CPES@pickereurope.ac.uk





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The survey was sent to adult (ages 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May, and June 2022





What do we think?

Clare Lerway

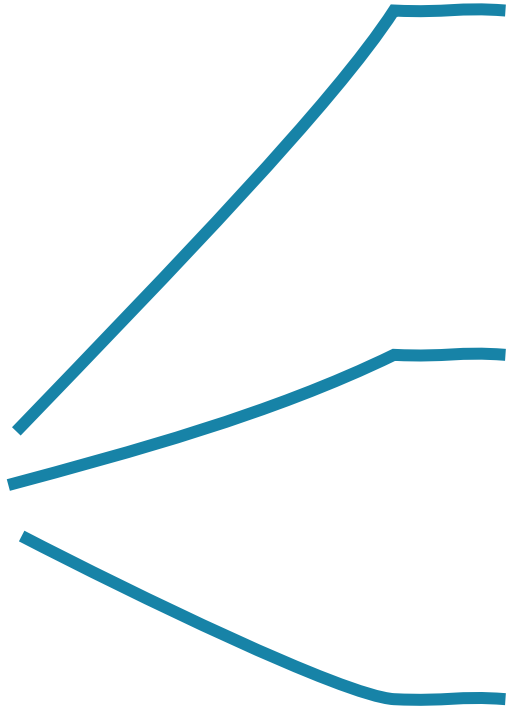
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Regional break out rooms



What do we think about the feedback?

What should we be celebrating?

What do we want to focus on going forward?



Case Study: The Royal Free London

Azmina Rose (Lead for Cancer Patient Experience & Macmillan Centres)

Kerry Guile (Consultant Nurse Oncology and Co-Clinical Director NCL SACT ERG)

CPES@PickerEurope.ac.uk

#pickerworkshops #cpes22



world class expertise  local care


Royal Free London
NHS Foundation Trust

Let's talk cancer

Kerry Guile, Consultant Nurse Oncology

Azmina Rose, Lead for Cancer Patient Experience & Macmillan Centres

Let's Talk Cancer - Overview

- An initiative based on our RFL NCPES results
 1. 6 principles of communication for staff
 2. 10 Top Tips for patients
 3. Interactive online training module

NCPES scores to improve

Question	National score	Royal Free 2019 score
Patient told they could bring a family member or friend when first told they had cancer	77%	67%
Hospital staff didn't talk in front of patient as if patient wasn't there	84%	77%
All hospital staff asked patient what name they prefer to be called by	71%	58%



Let's

talk

cancer

Output 1: 6 principles of communication

Let's talk **cancer**

Our commitment to you:

Introduce

We'll introduce ourselves to you and ask you how you'd like to be addressed.

Support

We'll ask you what support you have. Did you know your family member or friend is welcome to join you during your appointment?

Involve

We'll involve you and your companions in conversations about you.

Confirm

We'll clearly communicate your diagnosis, care plan and future appointments with you. Please tell us if anything is unclear.

Ask

We'll ask you what matters to you. Please tell us about your worries and fears.

Provide

We'll provide you with a named contact should you need advice.

positively  welcoming

actively  respectful

clearly  communicating

visibly  reassuring

MACMILLAN
CANCER SUPPORT

MACMILLAN
CANCER SUPPORT

MACMILLAN
CANCER SUPPORT

NHS SHN NHS SHN

NHS SHN NHS SHN



NHS
Royal Free London
NHS Foundation Trust

Let's talk cancer

Do six small things to make a difference to your patient's experience today:

<p>1 Introduce</p> <p>Introduce yourself: [Hello, my name is...], and ask your patient, and their companion, how they would like to be addressed.</p>	<p>2 Support</p> <p>Remind your patient that a family member or friend can be present and ask if they have any support.</p>
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**MACMILLAN
CANCER SUPPORT**



Output 2: Top 10 Tips

Top 10 Tips...

NHS
Royal Free London
NHS Foundation Trust

1



You can bring a family member or friend with you to any of your appointments.

2



Prescriptions are free for people who have cancer. You can speak to your specialist nurse or collect a form from the Macmillan Information Centre in Oncology Outpatients or your GP surgery.

3



There are parking concessions at the hospital for people being treated for cancer. Ask your clinical team for a concessionary form.

4



There is a Macmillan information centre in the oncology outpatient department on the ground floor opposite the blood room, where you can find information about all aspects of cancer support.

5



There is a Macmillan welfare advice team at the hospital who can provide help with money, housing, work and other practical issues – ask your specialist nurse or the Macmillan Centre to refer you, phone 020 7794 0500 ext 37698 or email rf.camdencab@nhs.net

6



The Maggie's Support Centre offers exercise sessions, counselling, emotional support, and complementary therapies. Go to the Sheila Sherlock centre (ground floor) and take the lift. Phone 020 3981 4840 or email royalfree@maggiescentres.org

7



You should have a named contact throughout your time with the Royal Free – if you're not sure who this is please ask one of the nurses in your team.

8



We want to know what matters to you – so please tell us.

9



We offer health and wellbeing events for all patients with a diagnosis of cancer, ask one of the nurses for more information or at the Macmillan Information Centre

10



Everybody with cancer is entitled to an individual assessment with a healthcare professional to enable them to raise concerns they may have and a care plan put in place to help to address them. Ask your specialist nurse for your assessment.

Top 10 Tips...

1 You can bring a family member or friend with you to any of your appointments. For certain appointments such as scans, any accompanying person may need to wait in the waiting area whilst you have the actual procedure.



2 You should have a named contact person throughout your time as a cancer patient. This person is usually called a Cancer Clinical Nurse Specialist (or CNS). If you're not sure who this is, please ask.



3 Everybody with cancer can have a personalised care and support plan. This is based on a structured conversation about your needs with a healthcare professional. It may also be called a Concerns Checklist or Holistic Needs Assessment (HNA).



4 There are Macmillan Information Centres at Barnet hospital, Chase Farm hospital and Royal Free hospital. You can pop in to talk to someone about your worries and concerns. You can also get information about different types of treatments, side effects, and tips on coping with them.



5 Cancer charities such as Nightingale (Enfield), Cherry Lodge (Barnet) and Maggie's (Hampstead) offer cancer support groups, complementary therapies, counselling and activities e.g. yoga. Please ask if you would like to know more.



6 If you need to reduce, or stop, work during your anti-cancer treatment and experience loss of earnings, please ask for an appointment with a Macmillan Welfare Adviser. They can give advice about benefits that you may be able to claim, and can also help you apply to a charity for a grant.



7 There may be parking concessions at the hospital for the days when you are receiving anti-cancer treatment. Please ask your Cancer clinical nurse specialist.



8 Prescriptions are free for people who have cancer. You can ask at the hospital, or the GP surgery, for form FP92A (application form for prescription charge exemption).



9 If you are on a low income and receiving certain benefits, you may be entitled to reclaim the cost of travelling to the hospital. Please ask for a claim form and submit it to the Cashier's office.



10 We want to know what matters to you, so please tell us. You can give feedback about your experiences in our hospitals by contacting PALS – the Patient Advice and Liaison Service (PALS). Please ask for more information.



Output 3: interactive online training module



These are Let's talk cancer's six steps to better communication:

Always
introduce



Always
support



Always
involve



Always
confirm



Always
ask



Always
provide



Always introduce

Please introduce yourself to me and ask me how I would like to be addressed.

Good examples?

- "Hello, my name is..."
- "This is my colleague..."
- Say your job title
- Say what you're responsible for

Risks if overlooked?

- Very likely, you'll come across as rude
 - Patient won't understand your (or colleagues') role in their care
 - Missed opportunity to build trust and rapport
-

Always support

Please mention that a family member or friend can be present and ask what support I have.

Good examples?

- "Have you brought anyone with you?"
- Remind patients they can always bring someone
- "Do you have anyone supporting you at home?"
- Ask if you can put patients in touch with support groups

Risks if overlooked?

- Patient not supported during clinical appointments
 - You don't have the full picture of your patient's situation
 - Missed opportunity to provide holistic care
-

Always involve

Please involve me and my companions in conversations about me – don't talk over me to other members of staff.

Good examples?

- Ask open questions
- Listen
- Avoid/prevent interruption by colleagues

Risks if overlooked?

- Very likely, you'll come across as rude
 - Patient may become disengaged in their care
 - Patient might miss important information about their care
-

Always confirm

Please clearly communicate my diagnosis, care plan and future appointments.

Good examples?

- Speak clearly and slowly as required
- Speak at an appropriate volume
- Avoid or explain highly technical language

Risks if overlooked?

- Patient is confused about their diagnosis
 - Care plans are not followed correctly
 - Appointments are missed
-

Always ask

Please allow me to discuss my worries and fears and ask what matters to me.

Good examples?

- Allow time for questions, even it requires an awkward silence
- Prompt patients to ask questions
- “There’s no such thing as a silly question”

Risks if overlooked?

- Patient is unclear about their diagnosis
 - You can’t check patient understanding
 - Patient may seek answers from inappropriate sources
-

Always provide

Please provide me with a named contact should I need advice.

Good examples?

- Quite simply, provide or confirm a named contact at the department

Risks if overlooked?

- Patient may become frustrated when contacting the department
- Patient may seek answers from inappropriate sources

Let's Talk Cancer - Impact

- MaST adoption at RFL pending
- Circa 1,000 learners across RFL & NCL
- Embedding in comms strategy & inductions
- Creation of mutual (generic) versions
- 6 other trusts adopted under licence
- Dissemination plans (primary care)

Overcoming Challenges and **Keys to Success**

- Time within job plans
- Pandemic

- Exec level buy-in
- Royal Free Charity funding
- Early Patient Involvement and Co-production
- National recognition – PEN award 2022



Let's Talk Cancer – Next Steps

Next steps...

- Additional Royal Free Charity funding
- Let's Talk franchise/brand...
- Let's Talk Chemotherapy – SACT & oral
- Nomination for PM Society Digital Award
- Engagement with new stakeholders e.g. primary care



Royal Free London
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Thank you

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world class expertise  local care



Closing remarks

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We welcome your feedback
<https://bit.ly/CPES22Feedback>

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