

Using qualitative and quantitative data: how to structure your research

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Quality Health

A specialist health and social care research organisation, working for public, private and not-for profit sectors, in the UK and overseas

- We design **innovative** data collection mechanisms to gather **insight** from patients, service users, staff and other stakeholders
- We use our **unique expertise** and experience to collect, process, analyse and present **information** in the most **meaningful** ways
- We work **collaboratively** with our clients to support service **improvements**, inform **change**, influence policy, and improve **outcomes**

We help our clients achieve **high quality** and **positive outcomes** in health, social care and other services

Key steps in generating data for Patient Advocacy

Work out what the problem is

- E.g. Do you have policy ideas you need to back up with evidence?
- E.g. Do you want to test a theory about patient experience?

Consider the bigger picture

- What is already known?
- Is there other relevant research?
- Are other Patient Advocacy organisations planning anything similar?

Have a clear analysis strategy

- Make sure you know from the start how you will analyse the data
- What exactly do you want to show, and to whom?
- Will qualitative findings (e.g. stories) be more powerful than quantitative (e.g. numbers)?

Be clear from the start how you want to use the data

Good data can help your organisation to...

Predict an outcome

- E.g. If patients' care is changed, how will this affect their overall wellbeing?

Explain a cause or consequence

- E.g. What has caused patients to report a drop in the standards of care?

Evaluate policy

- E.g. what has been the impact on patients of a change in policy or a new procedure?

Describe service provision

- E.g. What does high quality care look like from a patient perspective?

Develop good practice

- E.g. What do patients say would improve their care?

Empower patients

- E.g. What are the best ways to enhance patients' lives, and the lives of patients in the future?

Work out what your problem is: don't just run a survey for the sake of it!

Some good examples of *focused* patient advocacy research

European Cancer Patient Coalition

Cancer Associated Thrombosis Awareness Survey

Aims:

- To understand – and compare across countries – patients' awareness of CAT
- To map where, and when, patients get their information
- To identify gaps of information and support during the patient pathway

Some good examples of *focused* patient advocacy research

Acute Leukemia Advocates Network

ALAN Quality of Life Survey

Aims:

- To understand the quality of life of acute leukaemia patients at different points in the patient journey

Some good examples of *focused* patient advocacy research

All.Can International

Survey of Waste and Inefficiency in Cancer Care

Aims:

- To gather the views of cancer patients and carers into areas of waste and inefficiency in cancer care
- To gather examples of good practice, and areas for improvement

Some good examples of *focused* patient advocacy research

CML Advocates Network

CML Treatment Free Remission Survey

Aims:

- To understand the experiences of CML patients considering and undertaking Treatment Free Remission
- To compare different patient groups
- To consider the impact of different interventions and communications in this process

Main types of research to generate data

Literature review and desk research

- Reviewing the main ideas and research relating to your area of interest
- Accessing existing relevant data sets

Quantitative research

- Questionnaires delivered on paper, on-line, in person or by phone
- Structured interviewing

Qualitative research

- In-depth interviews, in person or by phone
- Focus groups
- Workshops

Many of the most successful research programmes use a combination of the above

Main types of research to generate data – pros and cons

PROs

Literature review and desk research

- Well-respected academic approach
- Relatively cheap
- Doesn't require external support

Quantitative research

- Best known and accepted research approach
- Gathers views from many patients
- Statistically significant results

Qualitative research

- Produces narrative rather than numbers
- Stories, quotes, and films can have more impact in advocacy campaigns

CONs

Literature review and desk research

- No new primary data
- Access to academic papers expensive
- Requires research skills

Quantitative research

- Can be expensive
- Sampling bias often an issue
- No depth behind the numbers

Qualitative research

- Expensive
- Usually only involves small numbers
- Difficult to argue it's representative

Typical research outputs

- Data tables (from qualitative surveys)
- Written commentaries of findings
- Breakdowns
- Powerpoint presentations
- Infographics
- Thematic analyses of qualitative research
- Quotes from interviews
- Films of patient stories
- Improvement events
- Formal papers for scientific journals
- Press releases and advocacy campaigns

You should be clear at the start about what you need, and how it will be used

Data Tables

YOUR JOB

1. Do you have face-to-face contact with patients / service users as part of your job?	Organisation 2018		Organisation 2019		All Organisations 2019	
	n	%	n	%	n	%
Yes, frequently	656	61%	526	60%	50,157	68%
Yes, occasionally	250	23%	186	21%	11,822	16%
No	162	15%	171	19%	12,120	16%
Missing	11		13		1,027	

For each of the statements below, how often do you feel this way about your job?

2a. I look forward to going to work.	Organisation 2018		Organisation 2019		All Organisations 2019	
	n	%	n	%	n	%
Never	37	3%	30	3%	1,721	2%
Rarely	110	10%	93	10%	6,661	9%
Sometimes	367	34%	313	35%	23,076	31%
Often	416	39%	336	38%	30,758	41%
Always	140	13%	118	13%	12,189	16%
Missing	9		6		721	
Positive Score	52%		51%		58%	
Negative Score	14%		14%		11%	
Base	1,070		890		74,405	

2b. I am enthusiastic about my job.	Organisation 2018		Organisation 2019		All Organisations 2019	
	n	%	n	%	n	%
Never	10	1%	15	2%	668	1%
Rarely	53	5%	41	5%	3,135	4%
Sometimes	241	23%	214	24%	15,563	21%
Often	446	42%	352	40%	30,512	41%
Always	313	29%	261	30%	24,001	32%
Missing	16		13		1,247	
Positive Score	71%		69%		74%	
Negative Score	6%		6%		5%	
Base	1,063		883		73,879	

Written commentaries of findings

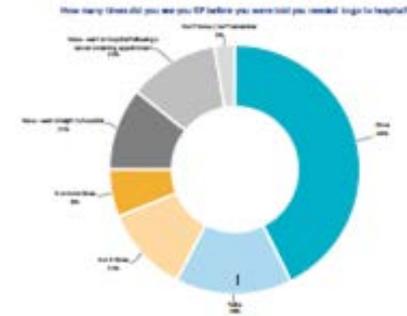


Survey results

Seeing your GP

Respondents were asked how many times they saw their GP about the health problem caused by cancer, before they were told they needed to go to hospital about cancer.

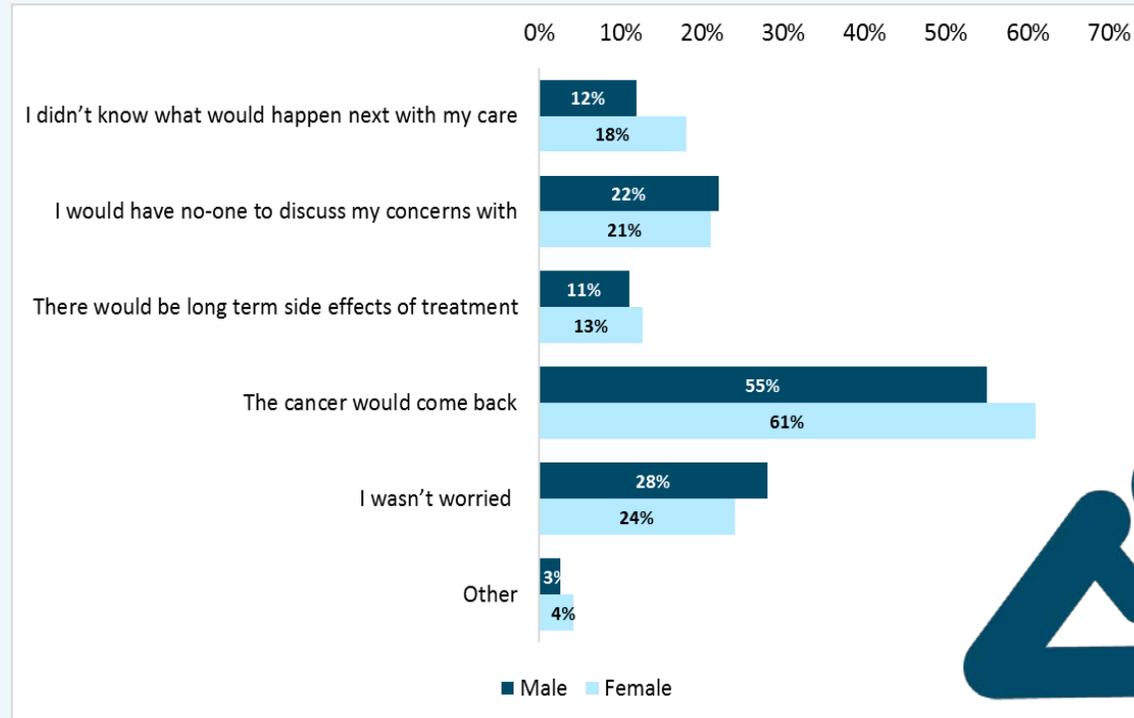
Of those who saw their GP, **77%** said that they saw their GP only once or twice, **15%** said that they saw their GP three or four times; and **8%** said that they saw their GP five or more times.



When asked how they felt about the length of time they had to wait before their first appointment with a hospital doctor, **84%** of respondents said that they were seen as soon as they thought was necessary. This is significantly higher than last year's score of 83%.

Presentations: a breakdown

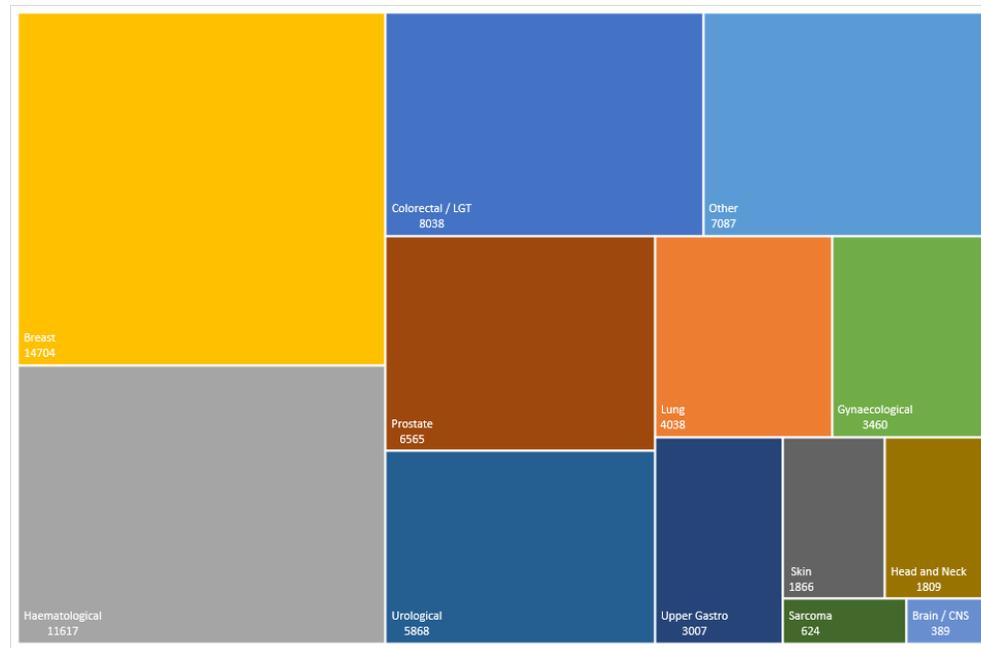
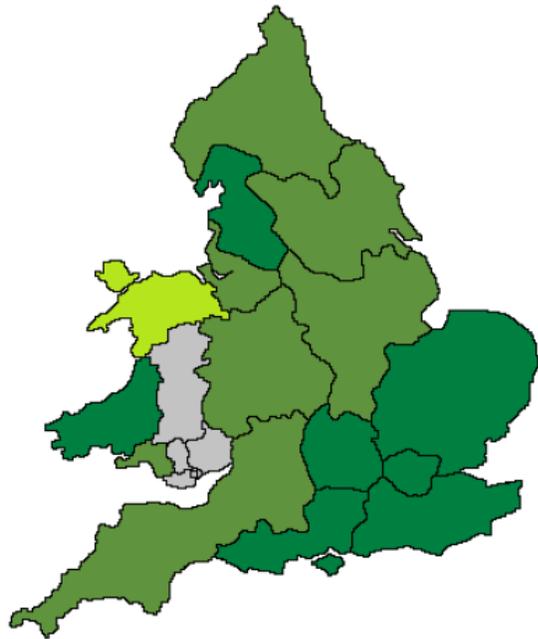
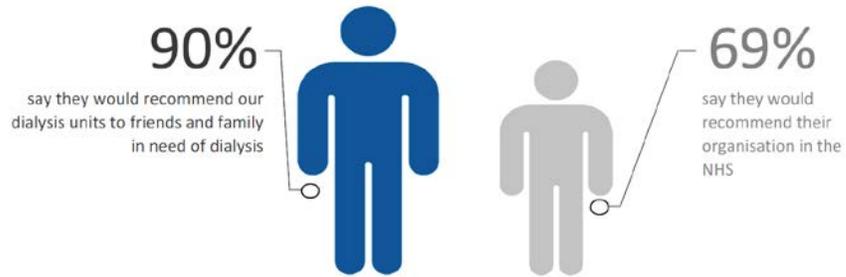
Main worries after the end of treatment * - by Gender



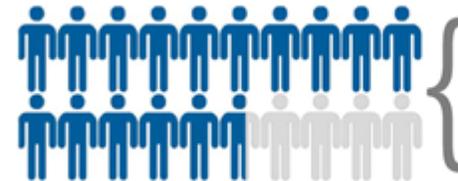
*Respondents could select all answer options that applied (tick all that apply)
Q7 / base = all respondents - What are the main worries you had after your treatment ended?
Males (n=450) Females (n=560)

Infographics

ORGANISATION v NHS



78%



would recommend our dialysis units as a place to work v 59% would recommend their organisation in the NHS.

Thematic analysis



Treatment

continued

Two-thirds (63%) said that they did not need further treatment following the surgical intervention they received. However, the long term effects of treatment were something that many of the women were now dealing with. For example isolation, sickness, fear and tiredness were also reported.

Each woman had a different experience of treatment with the impact often influencing physical, emotional and practical aspects of their lives. For some the frequency and intensity of the treatment resulted in significant changes to their day to day routine. For others their family or work life were where they felt the most disruption or pressure.

“ Age 33
Stage 1b1

The radiotherapy wasn't painful. I had all the help I needed from my CNS. I asked my husband to leave me to it, although he did come with me for chemo appointments. It was sad to see all the other patients there, especially the older ones. It made me put my own treatment into perspective. The side effects all kicked in at once in the second week. I was so tired; I just didn't want to do anything. All the plans I had made in my heads to do things alongside my treatment went out of my head. The chemo wasn't too bad, but it was painful. The radiotherapy gave me the worst side effects.

“ Age 36
Stage 1b

The first session of chemotherapy wasn't too bad. Then I went off to have radiotherapy. I started to have bad reaction to the treatment, I had nausea and went into the menopause.

“ Age 71

Towards the end of the treatment I became very tired and my hair thinned. I suppose it was everything leaving the body. Then I started to get lots of side effects. I seemed to get everything going including diarrhoea, cystitis.

“

Stage 1b1
Age 49

I felt bewildered and withdrew from life a bit, but this was changeable. People were visiting and flowers and cards were being sent, but I didn't want this as it meant I was poorly.



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Discrete-choice experiment to analyse preferences for centralizing specialist cancer surgery services

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☰ SECTIONS

 PDF  TOOLS  SHARE

Abstract

Background

Centralizing specialist cancer surgery services aims to reduce variations in quality of care and improve patient outcomes, but increases travel demands on patients and families. This study aimed to evaluate preferences of patients, health professionals and members of the public for the characteristics associated with centralization.

Methods

A discrete-choice experiment was conducted, using paper and electronic surveys. Participants comprised: former and current patients (at any stage of treatment) with prostate, bladder, kidney or oesophagogastric cancer who previously participated in the National Cancer Patient Experience Survey; health professionals with experience of cancer care (11 types including surgeons, nurses and oncologists); and members of the public. Choice scenarios were based on the following attributes: travel time to hospital, risk of serious complications, risk of death, annual number of operations at the centre, access to a specialist multidisciplinary team (MDT) and specialist surgeon cover after surgery.

Results

Responses were obtained from 444 individuals (206 patients, 111 health professionals and 127 members of the public). The response rate was 52.8 per cent for the patient sample; it was unknown for the other groups as the survey was distributed via multiple overlapping methods. Preferences were particularly influenced by risk of complications, risk of death and access to a specialist MDT. Participants were willing to travel, on average, 75 min longer in order to reduce their risk of complications by 1 per cent, and over 5 h longer to reduce risk of death by 1 per cent. Findings were similar across groups.

Conclusion

Respondents' preferences in this selected sample were consistent with centralization.



Interviews

The quotes in this video are real patient comments collected in the All.Can patient survey. They are read out by actors.

Films of patient stories



Some common problems...and how to avoid them

Not involving patients

- Coproduction of research design
- Patients and patient advocates on Steering Groups
- Patients involved in reviewing and testing survey materials

Not focusing on a specific issue - being too ambitious in scope

- Identify the theme/issue you're interested in
- Keep it short
- Don't just run a survey for the sake of it!

Not knowing what's already been done

- Talk to the experts
- Carry out some form of literature review

Some common problems...and how to avoid them

Not knowing what others are doing

- Network with other patient advocacy groups, in other countries - It's likely someone else is interested in the same issue

Lack of testing and piloting before fieldwork

- Don't rush into implementation
- Test survey materials thoroughly
- Formal Cognitive Testing *always* identifies issues

Asking the wrong people

- Think about the sample of patients you want to hear from
- Design your research framework to generate a representative sample
- Don't just listen to the same old voices

Some common problems...and how to avoid them

Choosing the wrong delivery mechanism

- Using an external agency can be expensive and add complexity
- But carrying our research in-house risks lack of independence; and most organisations don't have the skills and capacity
- There will be times where both of these are right: consider carefully for each piece of research

Not knowing how you'll use the results

- Be clear at the start about what you need, and how it will be used

Talk as much as possible to other Patient Advocacy Groups about their experiences

