

# How to **CREATE** evidence for advocacy impact?

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# Methodology is key...



# Case Study: Living with Leukaemia

Leukaemia Care

Survey conducted in partnership with Quality Health

# Living with Leukaemia: Project Aims

- The aim was to provide further evidence on UK leukaemia **patient experience**
- Understanding the needs of patients with different forms of leukaemia
- This project was designed as a follow up to NHS England's annual Cancer Patient Experience Survey (CPES)
- Two iterations of the survey
  - September 2016 to December 2016 – Published September 2017
  - September 2017 to December 2017 – Published September 2018

**Leukaemia Care**  
YOUR Blood Cancer Charity

Leukaemia Care  
**Living with Leukaemia**

2018 Report



[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

# Living with Leukaemia: Methodology – Cohorts

## CPES

Contacting patients with leukaemia who were identified using the National Cancer Patient Experience 2016 Survey data

## Leukaemia Care

Contacting leukaemia patients from Leukaemia Care's database. Those with consent to contact, and who had a valid postal address, but no email address recorded on the Leukaemia Care database.

## Anonymous

An anonymous online survey of the wider UK blood cancer community. This arm also included patients from the Leukaemia Care database that Leukaemia Care had consent to contact, and who had a valid email address.

# Living with Leukaemia: Questionnaire Design



Aims – Exploring UK leukaemia patient experience



Topics – Following the journey from diagnosis onwards



Testing – To refine the content



Comparability – between 2016 and 2017 versions



## Patient Survey

This questionnaire is about your care and treatment for a blood cancer. Its purpose is to provide information, which can help the NHS and Leukaemia CARE monitor and improve the quality of health services for future patients with blood cancer.

Taking part in this survey is voluntary. Published reports will not contain any personal details.

Who should complete the questionnaire?  
The questions should be answered by you, as the person who has been treated for a blood cancer. If you need help to complete the questionnaire, the answers should be given from your point of view – not the point of view of the person who is helping.

Completing the questionnaire  
For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

### IMPORTANT INFORMATION

To make sure the information we collate is useful, we need to collect some personal details from you and access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the care and treatment people receive. These statistics will be used to compare the differences in care and treatment by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to Leukaemia CARE to analyse the data.
- Your personal information will be handled securely and anonymised after analysis and before any publication.
- Your personal information will not be released by anyone working on behalf of Leukaemia CARE unless required by law or where there is a clear overriding public interest.
- You can withdraw the information you give Leukaemia CARE in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on 0800 783 1775

# Living with Leukaemia: Outcome

 **Response Rates – 2329 leukaemia patients**

 **Publish the results!**

 **Plans: Patient, Carer and Healthcare Professional**

### Leukaemia Care The Emotional Impact of Watch and Wait for CLL

YOUR Blood Cancer Charity

**Background:** A cancer diagnosis can have negative effects on a patient's mental health, watch and wait (WW), or active monitoring, is a common course of action for chronic lymphocytic leukaemia (CLL) patients. WW has been identified as a particular source of distress for CLL patients. Evans et al (2016) conducted interviews with CLL patients and found that those on WW were as likely to experience depression and anxiety as those in active treatment.

**Aims:** Leukaemia Care conducted a survey of CLL patients face, particularly those patients on watch and wait (WW).

**Conclusion:** This survey highlights areas of need to reduce the psychological impact of a CLL diagnosis. There is a need to improve communication at diagnosis, including a tailored explanation of CLL and the rationale for WW, providing high quality written information to take away. The findings suggest that patients on WW need support, such as CNS access, as much as those starting treatment.

**Support provision:** Patients placed on watch and wait at diagnosis are less likely to be given information on emotional support than those starting treatment (38% vs. 42%), reducing to 29% for those still on watch and wait. Those on watch and wait at diagnosis were also less likely to be offered additional support (such as support groups, body scans or counselling) than those starting treatment (straight away 53% vs. 69%, reducing to 39% for those still on WW).

**Emotional impact of watch and wait:** Comparison with responses from other leukaemia patients suggests CLL patients are the least likely to be affected emotionally by their diagnosis. However, certain groups of CLL patients are more likely to be emotionally affected by their diagnosis than the overall figure suggests.

**There was a correlation between:** feeling worried and being given understandable information regarding watch and wait.

**Of those on watch and wait at diagnosis, only 60% fully understood the reasons for being placed on watch and wait (increase to 68% for those still on watch and wait at time of survey).**

**53% said they had concerns or worries about watch and wait.**

**The majority (58%) of patients in the UK are given written information about watch and wait.**

**There is a correlation between:** feeling worried and being given understandable information regarding watch and wait.

**The number of CLL patients still on watch and wait who are reporting feeling depressed or anxious more often since diagnosis (77%) is equivalent to the highest level of emotional impact reported by patients with any leukaemia type (in other Leukaemia Care surveys).**

**Access to a clinical nurse specialist (CNS) has been identified by most English as a key driver of improved patient experience, yet the majority of CLL patients do not have access.**

### Leukaemia Care The Financial Impact of Acute Leukaemia

YOUR Blood Cancer Charity

**Background:** The financial impact of cancer is well documented in the "Cancer's Hidden Price Tag" report commissioned by UK cancer charity Macmillan. It was found that 3 out of 5 patients are affected and, on average, are £50 a month worse off because of a cancer diagnosis. The report identified that those in work at the time of diagnosis experience the highest financial burden. NCI's English's 2016 Cancer Patient Experience Survey (CPES) asked if hospital staff gave information about how to get financial help they might be entitled to, only 41% of leukaemia patients who would have liked this type of information were given it.

**Aims:** Leukaemia Care surveyed acute leukaemia patients, to identify key concerns and issues faced throughout their cancer journey, including the financial impact.

**Summary/conclusion:** Most acute leukaemia patients report experiencing financial issues and often must give up work, either permanently or temporarily, which could also impact on their financial situation for years to come. Not all patients are receiving information to help them find financial assistance. The support and advice given by hospitals about the financial impact of leukaemia needs to improve, incorporating signposting to specialised financial support. In addition, further work could be done to determine whether the patients who do seek assistance get help that is adequate for their needs. Financial worries are an additional stress for cancer patients that need to be addressed by charitable organisations and policy makers alike.

**Most patients (64% AMM and 76% ALL) were in work or education at the time of their diagnosis. Those in work or education were more likely to report a negative financial impact.**

**The negative financial impact was associated with both an increase in costs and a reduction in income.**

**Most patients (64% AMM and 76% ALL) were in work or education at the time of their diagnosis. Those in work or education were more likely to report a negative financial impact.**

**Of those in work or education, 65% of ALL patients and 75% of AMM patients reported having to stop work or education either permanently or on a temporary basis.**

**Patients often need help directing to sources for financial assistance and information. Whilst a high proportion of patients receive information about their leukaemia, fewer patients receive practical information, such as guidance on managing the financial impact of acute leukaemia.**

**All age groups report an impact on their work or education, but as age increases the impact is more likely to be permanent.**

**This could reflect the fact that people are closer to retirement, so they may only have to take a couple of years off work for this to become a permanent change.**

# Case Study: Acute Leukemia Global Quality of Life Survey

Acute Leukemia Advocates Network (ALAN)

Survey conducted in partnership with Quality Health

# ALAN Survey: Overview



Global Quality of Life Survey (10+ Languages)



Aim: identify and measure Quality of Life issues, raise awareness and change practice



Insights > Development > Publication



Timelines: Fieldwork from March 2019 to July 2019

# ALAN Survey: Methodology – Survey Layout



Demographics: Including self-reported acute leukemia diagnosis



HM-PRO

Goswami, Salek, Ionova, Oliva et al. HM-PRO: A Novel Patient-Reported Outcome Measure in Hematological Malignancy for Use in Clinical Practice. Blood 2017 130:2176



Hypotheses Questions: Test against HM-PRO to assess how they impact on quality of life



Follow Up Questions: To gather further information on patient experience of each hypotheses

# ALAN Survey: Methodology - Hypotheses

- Our hypothesis is that patients reporting lower scores in each of these areas will report a lower quality of life score overall (measured using the HM-PRO)



Physical symptoms and side effects of acute leukaemia and treatment

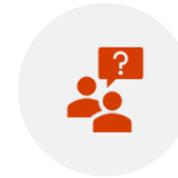


Emotional impact of acute leukaemia and treatment

- The hypotheses were:
  - designed in advance
  - based on a literature search and input from patient advocates and clinicians
  - questions designed to match hypotheses and show statistical significance of results



Physical and mental health



Information to help you understand and manage your acute leukaemia



Ability to perform meaningful activities (physical activities, hobbies or interactions with friends, family and the 'outside world')



Well-being and lives of your carers, friends or family

# How to **USE** evidence for advocacy impact?

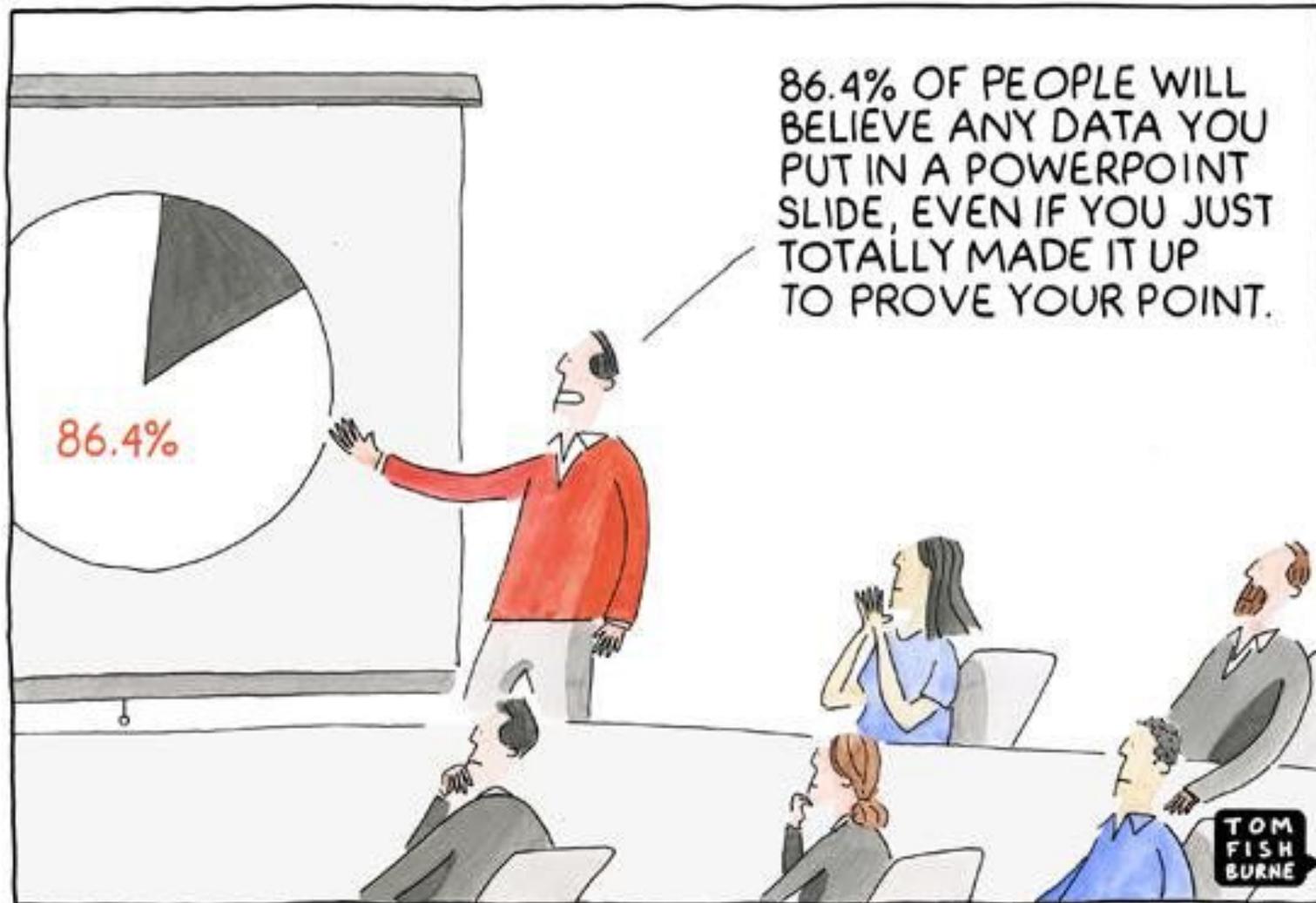
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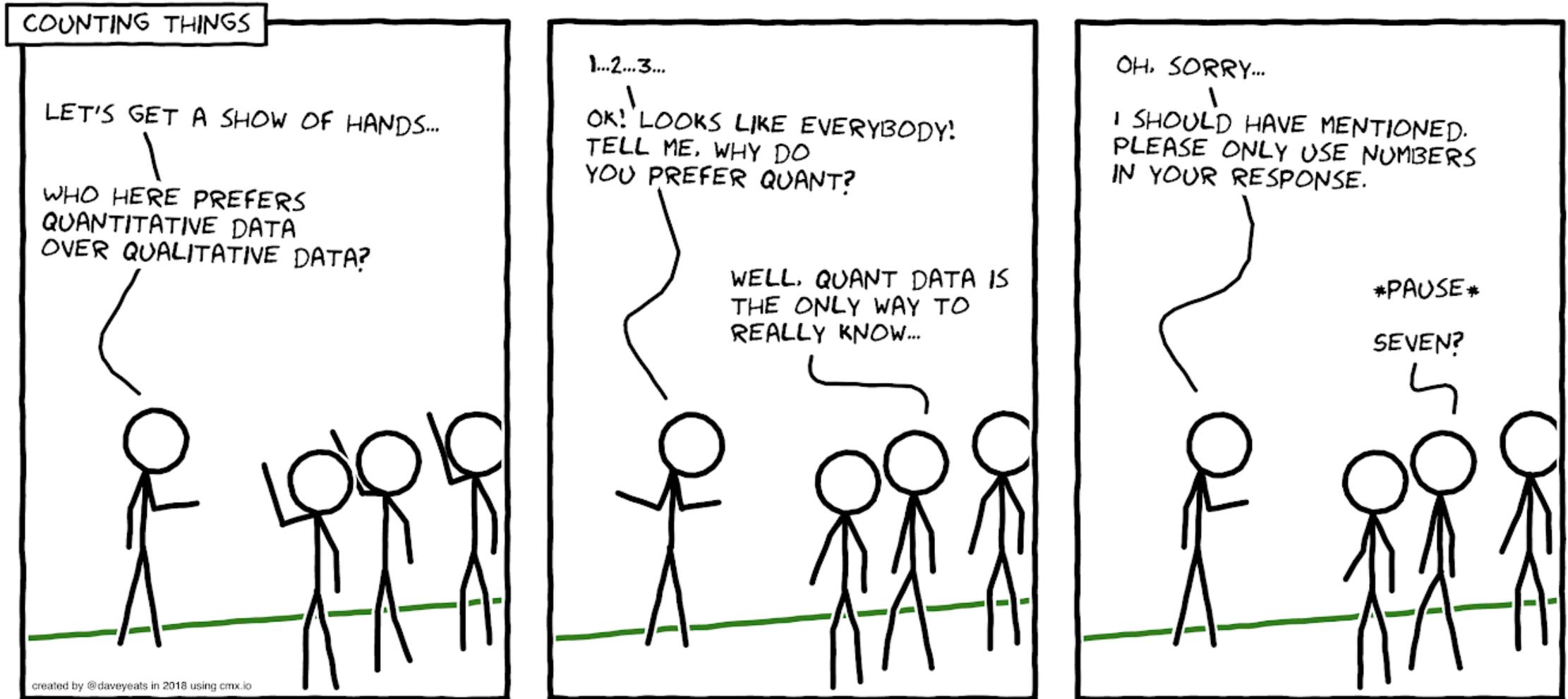
# Why use evidence? Credibility



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# What to use?

## Different evidence is needed for different situations



# How to use evidence...

- Listen to the evidence
- Act on the evidence
- **DO NOT** use evidence just to back up your existing point of view

**“Follow the evidence wherever it leads, and question everything”**

Neil deGrasse Tyson



I see here that I'm right about everything.

# STOP: Does your evidence show what you think it does?



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## Is your methodology correct?

- Did you ask the right question?
- Did you ask the right people?
- Did you ask enough people?
- Is your conclusion what the data actually shows?
- Is it statistically valid?

# Defining Unmet Needs

Remember to “Follow the evidence...”, **USE** it to...

- Identify: What are the issues to focus on
- Measure  
Quantify issues (e.g. the % of patients experiencing)  
Differences between particular groups. such as demographics, cancer type, regions, time
- Solutions: Create a set of recommendations to address
- Further Questions - Is there anything you need more evidence on? e.g. Understanding the different perspectives of patients, carers and HCPs

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# Organisational Strategy

- How are you going to address the unmet needs? How can your organisation work on the recommendations?

## Questions to think about:

- What are you already addressing?
- What should you do differently?
- What do you need to do more of?
- What are you not doing?
- What can you **NOT** do? What should be worked on by others?

## Collect Further Evidence

- Use Key Performance Indicators (KPIs) – to measure outcomes and impact
- Collect data and compare – e.g. performance across years

**Leukaemia Care**  
Supporting those affected by blood cancer for 50 years

## Strategic plan for Leukaemia Care 3 years – 2019 to 2022

Presented to the Trustee Board  
23 January 2019



# Developing New Services

One you have identified an unmet need to focus on...

- Designing the service – what exactly do you need to address?
- Use evidence for your funding application
- Use feedback to refine existing services
  - Use Key Performance Indicators (KPIs) – to measure outcomes and impact
  - Individual feedback from users (e.g. survey)
- Consider running a small PILOT to show it works?

## Emotional Impact



# Campaigns – Awareness and Early Diagnosis

## Understand your audience

- Public v Patient – are you targeting a specific demographic?
- What does the audience already know?

## Use Evidence

- Your own (e.g. survey)
- External (e.g. NCIN Routes to Diagnosis)

## Consider your message

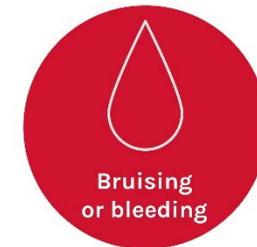
- What does the audience need to know?
- Where to focus? – e.g. leukaemia, blood cancer or cancer

## Example: explaining how to #SpotLeukaemia

- Leukaemia is a cancer
- It affects people of all ages
- The most common symptoms experienced before diagnosis:



Fatigue



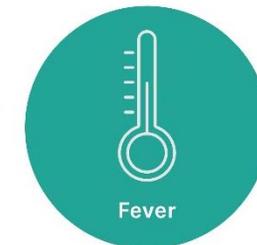
Bruising  
or bleeding



Repeated  
infections



Feeling  
weak or  
breathless



Fever



Joint or  
bone pain

# Campaigns - Policy

## Understand your audience

- Just 26% of MPs know 'quite a lot' or 'a great deal' about blood cancer. (YouGov, 2018)

## Use Evidence

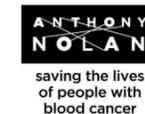
- Tailor the evidence to your audience – e.g. regional
- It doesn't have to be your own – e.g. incidence or prevalence

## Consider your message

- What will have the impact with this audience?
- Where to focus? – e.g. leukaemia, blood cancer or cancer

## Example: explaining why 'Blood Cancer' matters from their perspective?

- The fifth most common type of adult cancer
- The most common cancer amongst children
- The third most fatal cancer



# Campaigns – Patient Issues

- Using evidence to develop and run campaigns to address specific issues
- **Audience** – Patients? Clinical community?
- **Evidence** – Tailor to look at differences? Can you do a specific survey? Or breakdown of an existing survey?
- **Message** – What are you trying to change?

## Example: ‘Watch Wait Worry’ campaign

- We developed:
  - Evidence Report – for clinicians
  - Supportive guidance for CLL patients on watch and wait
  - Social media campaign
- Ongoing – Poster at EHA on the emotional impact of watch and wait for CLL



# Health Technology Appraisals (HTA)

- Different HTA processes have different opportunities for patient organisations to get involved
- In most cases the consideration of patient perspective is **qualitative**, so it is difficult to understand the impact on decision making
- You can create **quantitative** evidence (e.g. patient surveys), but at present there is no mechanism for the inclusion of such evidence
- Focus on:
  - Influencing the areas that affect cost-effectiveness
  - Impact not involvement
  - Explaining existing evidence (e.g. trial) and the benefit from a patient perspective

**NICE**  
National Institute for  
Health and Care Excellence

# Regulators – European Medicines Agency (EMA)

## Example – Blinatumomab, MRD Activity

- Initial CHMP Negative Decision
- Don't just follow the process!
- Explanation that:
  - Realities of the setting – e.g. outcomes and unmet need
  - Benefits of the treatment – e.g. from clinical trial
  - **Evidence** of benefit - from the patient perspective
  - Explanation of benefits not captured in the trials
- Outcome: Positive CHMP and EMA approval



