

# Living with Leukaemia

Leukaemia Care Patient Experience Survey (2016)

**Zack Pemberton-Whiteley**

**CML Horizons - Warsaw – 5<sup>th</sup> May 2018**

Campaigns and Advocacy Director, Leukaemia Care (UK)

CML Advocates Network – Steering Committee – Western Europe

Chair, Acute Leukemia Advocates Network (Global)

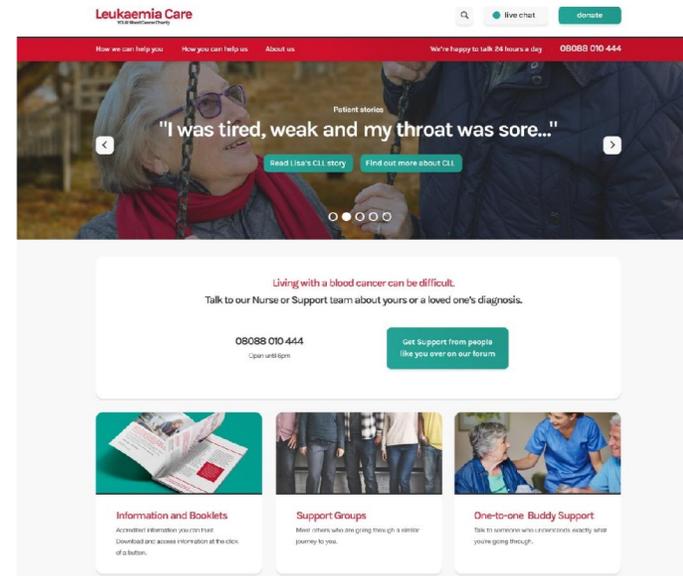
[zackpw@leukaemiacare.org.uk](mailto:zackpw@leukaemiacare.org.uk) or 01905 755977

## Leukaemia Care - Introduction

- Founded in 1969
- UK based blood cancer charity
- Our support services include:
  - Website
  - Helpline – Nurse Advisors
  - Online Forum
  - Information Booklets
  - Support Groups
  - Conferences
  - Quarterly Magazine

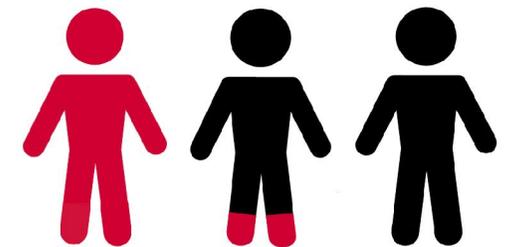
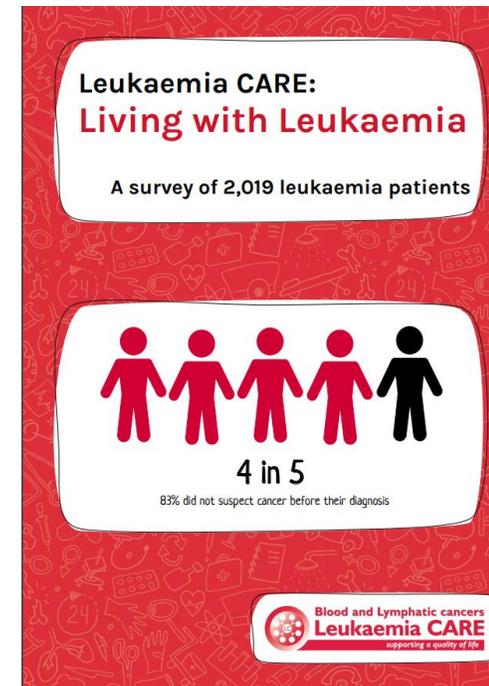
**Leukaemia Care**  
YOUR Blood Cancer Charity

**Who we are,  
and what  
we do.**



# Leukaemia Care - Survey

- Living with Leukaemia Survey
  - 2019 leukaemia patients
  - CML Breakdown (292)
  - Launched in Houses of Parliament

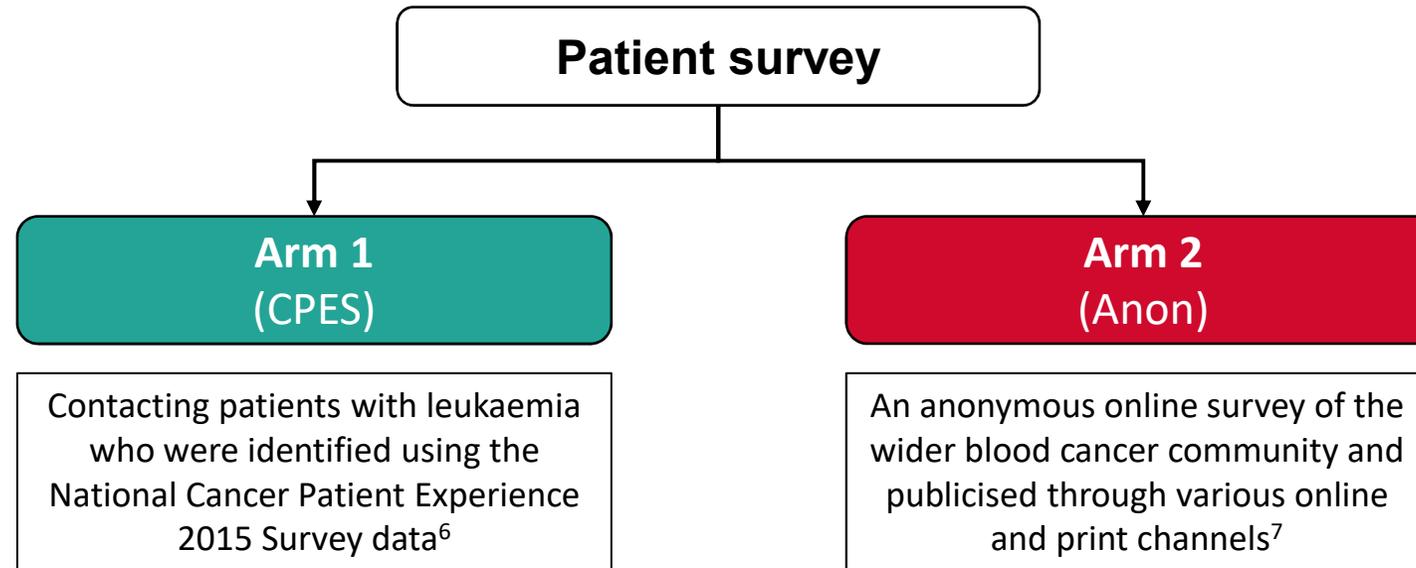


<http://www.leukaemiacare.org.uk/living-with-leukaemia>

# Introduction

- This project was designed as a follow up to NHS England's annual Cancer Patient Experience Survey (CPES)<sup>1</sup>
- The aim was to provide further evidence on leukaemia patient experience<sup>2</sup> and support needs<sup>3</sup>
- It focused on the varying needs of patients with different forms of leukaemia<sup>4</sup>
- Timescales – Fieldwork was run between 26 September and 16 December 2016<sup>5</sup>

# Patient Cohorts



- Through exploring two distinct cohorts the survey sought to identify areas where leukaemia patients reach out to charities for support, as well as areas that patients need support but currently have nowhere to reach out to<sup>8</sup>

# Questionnaire Design

- The questionnaire was developed and designed over a number of months in 2016, following detailed discussion between Leukaemia Care and Quality Health<sup>9</sup>
- The questionnaire was tested by 9 patient volunteers. This exercise contributed towards refining the questionnaire into a finished version<sup>10</sup>
- There were two versions of the questionnaire. Arm 2 (Anon) included 8 additional questions to capture data already known from the CPES cohort<sup>11</sup>

# Questionnaire Topics<sup>12</sup>

- Before Diagnosis
- Finding out what was wrong with you
- Treatment and care – including ‘watch and wait’
- Living with blood cancers
- Support for people with blood cancers
- Care from your GP after diagnosis
- After treatment
- Testing and monitoring
- Your views on potential new treatments
- About you
- Other comments

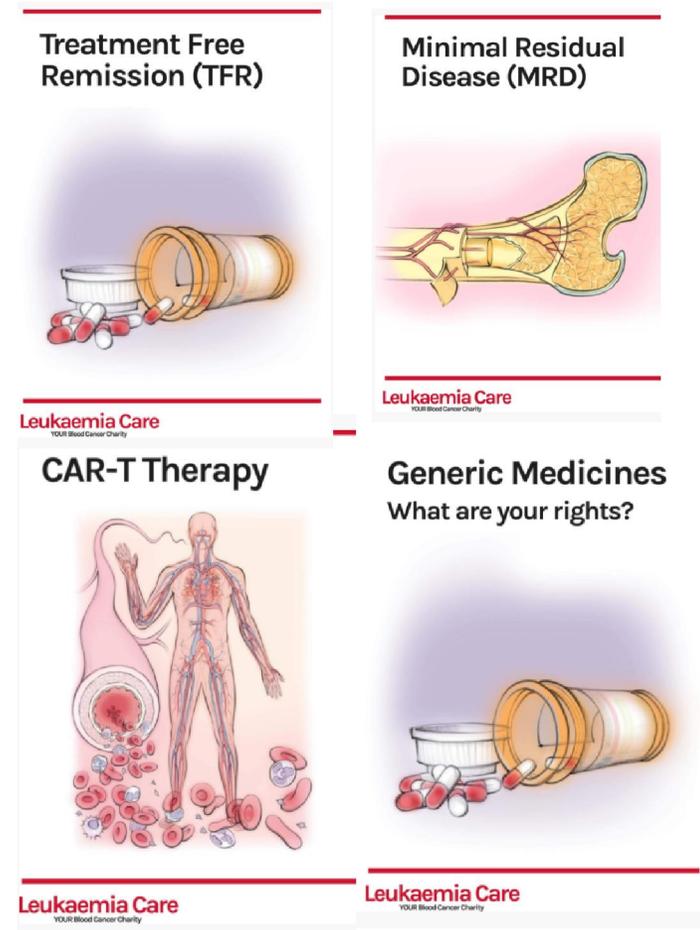
# Response Rates

- The number of leukaemia respondents were as follows<sup>13</sup>:
  - Arm 1 (CPES) 1320 (78% response rate)
  - Arm 2 (Anon) 699
  - TOTAL 2019
  
- The breakdowns by leukaemia type<sup>14</sup>:
  - Acute lymphoblastic leukaemia (ALL) 151
  - Acute myeloid leukaemia (AML) 373
  - Chronic lymphocytic leukaemia (CLL) 1007
  - **Chronic myeloid leukaemia (CML) 292**
  - Other leukaemia 206

What have we used the survey  
evidence for?

## Leukaemia Care – Advocacy

- Health Technology Appraisals (NICE, SMC, AWMSG)
- Campaigns
  - [Spot Leukaemia](#)
  - [#myCNSmatters](#)
  - [I wasn't born yesterday](#)
  - [Watch, Wait, Worry](#)
- Advocacy Toolkit
- Individual Advocacy



## Leukaemia Care - Awareness

- BCAM – Spot Leukaemia
  - 15,000 Symptoms Cards
  - 3 million reached on social media
- GP Education
  - Over 2000 GPs signed up to online course
  - PILOT Conference (Jan 2018 - 40 GPs)



## Awareness of Leukaemia

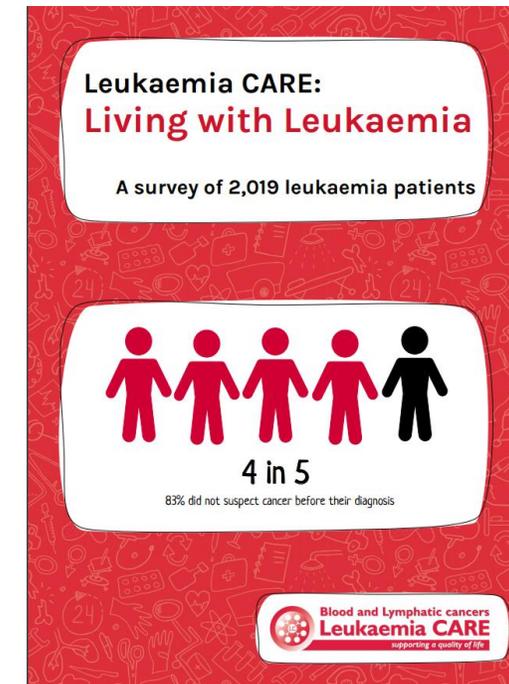
- Leukaemia (as a term) is well known, with 83% of patients reporting that they had heard of it before their diagnosis. However, there is little public understanding of leukaemia, with only a third of patients reporting that they knew anything about it<sup>15</sup>
- People are not aware of the symptoms that could indicate a potential leukaemia. 44% of acute leukaemia patients and 66% of chronic leukaemia patients said they waited over a month before going to see their GP<sup>16</sup>.
- **Recommendation:** There is a need for greater public knowledge of leukaemia. That leukaemia is a cancer of the blood, that can affect people of all ages and the symptoms associated with it<sup>17</sup>.
- Spot Leukaemia campaign: [www.leukaemiacare.org.uk/Spot-Leukaemia](http://www.leukaemiacare.org.uk/Spot-Leukaemia)

# Awareness of Leukaemia

- Less than half (44%) of respondents felt their GP had a complete understanding of blood cancers<sup>18</sup>.
- NCIN routes to diagnosis report<sup>19</sup> shows the percentage (%) of cancer patients diagnosed via emergency presentation from 2006-2015:
  - Cancer (excl. NMSC) – 22%<sup>20</sup>
  - Leukaemia (AML, ALL, CML and CLL combined) – 37%<sup>21</sup>
- **Recommendation:** There needs to be an overall improvement of awareness for the signs and symptoms of leukaemia, amongst healthcare professionals who can aid in earlier diagnosis (such as general practitioners)<sup>22</sup>
- Leukaemia Care GP education programme:  
[www.leukaemiacare.org.uk/gp-training](http://www.leukaemiacare.org.uk/gp-training)

## Future Plans?

- 2016 Survey
  - Survey – September 2016 to December 2016
  - Report - Launched September 2017
- 2017 Survey
  - Survey – September 2017 to December 2017
  - Launched September 2018
- 2018 Survey
  - Survey – September 2018 to December 2018?
  - Launched September 2019?



Find out more:

[www.leukaemiacare.org.uk/living-with-leukaemia](http://www.leukaemiacare.org.uk/living-with-leukaemia)