

Is CML too niche for policy makers?

#LeukaemiaLevy campaign, and other examples

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Is CML too niche for policy makers?

Yes?

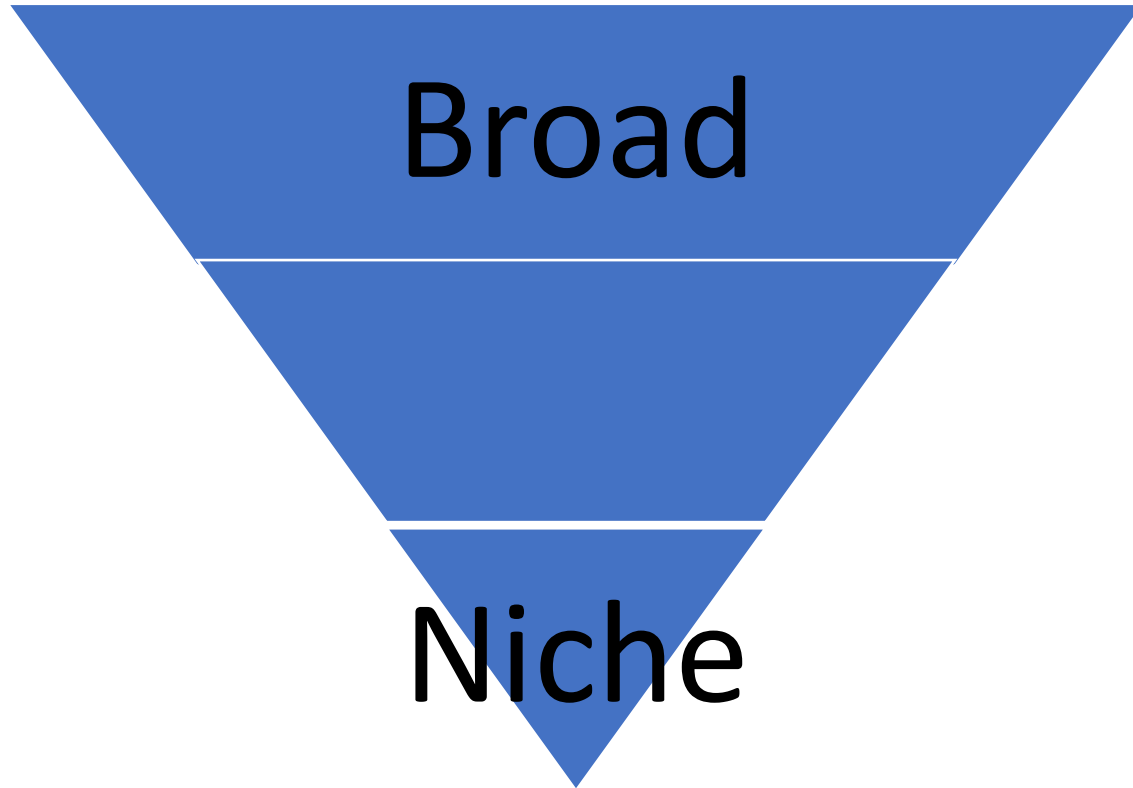
No?

It depends... where are you starting from?
Where do you want to go?

About us

- National charity; 4 systems
- All leukaemia, MPN and MDS + coalition work (blood cancers, rare cancers, all cancers...)
- 10 shared issues + the specifics (generics, TFR etc.)
- Team of 3 + me

So when to talk to policy makers?



Who?

How?

Why?

Leukaemia Care

YOUR Blood Cancer Charity

No such thing as a “policy maker”



HM Government



Norfolk and Waveney
Integrated Care Board



Civil Service



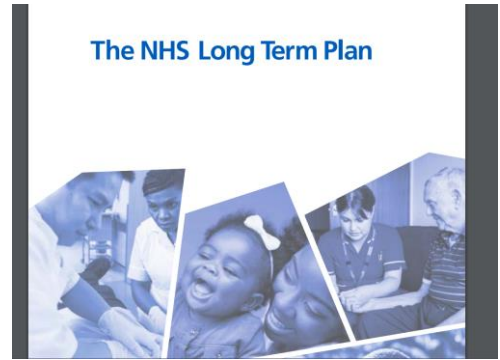
House of Commons



Stakeholders have different power and remit



HM Government



Home > health and social care > public health > health conditions > cancer research and treatment > 10-Year Cancer Plan: call for evidence



Call for evidence outcome
10-Year Cancer Plan: call for evidence
Updated 17 May 2023

Applies to England

Contents

[Executive summary](#)

[Foreword from the Secretary of State](#)

[The 10-Year Cancer Plan for England](#)

[Questions](#)

[How to respond](#)

Executive summary

This call for evidence has been extended by a week, to give more people a chance to put forward their views and inform the government's new 10-Year Cancer Plan.

This call for evidence will now close at 11:45pm on 8 April 2022.

This call for evidence will inform the development of the government's 10-Year Cancer

What are you asking for?

Tell them there is a problem? **Some are easier than others**








New commitments?

Mentions of CML?

Changes to the way things
are done?

“The issue is frequently not one of whether a policy exists, but whether the policy has been consciously developed”

ADVOCACY CANVAS

 <p>PROBLEM</p> <p>What are the key issues you want to address with your advocacy campaign?</p> <p>Who is most affected by those issues?</p>	 <p>SOLUTION</p> <p>What are the proposed policy solutions to the problem?</p>	 <p>ADVOCACY GOAL</p> <p>What is your longer-term goal?</p>	 <p>ADVOCACY STRATEGIES & ACTIONS</p> <p>How are you reaching your intended outcomes? Define the key strategies of your campaign?</p> <p>What are the key actions you need to do in the short-term?</p>	 <p>KEY INFLUENCERS & CHANGES WE WANT TO SEE IN THEM</p> <p>Who are the key groups or individuals you should target with your advocacy?</p> <p>What are the changes you expect/like or love to see in their behaviours (these are your intended outcomes)?</p>
 <p>RESOURCES</p> <p>(time, staff, funds, assets, existing materials relevant for the campaign)</p> <p>What resources do your partners and you have at hand to implement the campaign? What additional resources are required to run the campaign effectively?</p>		 <p>KEY PARTNERS</p> <p>Who are the key partners, allies and networks you need to collaborate with, and what type of partnerships do you envision?</p>		

Case study: #LeukaemiaLevy

Problem:

- Many financial issues
- But most common are energy bills and hospital travel
- Worse for acute patients, CAR-T patients especially





PROBLEM

What are the key issues you want to address with your advocacy campaign?

Who is most affected by those issues?

Case study 1: #LeukaemiaLevy

Solution (and existing policies):

 SOLUTION <i>What are the proposed policy solutions to the problem?</i>
 RELEVANT POLICIES <i>What are the main policies related to the problem?</i>

- For both issues, we needed direct support (discounts or cash support)
- Overall political atmosphere not good for this
- energy support was about to end, travel support is there for some

Case study 1: #LeukaemiaLevy

Overall goal and demands:


 ADVOCACY GOAL <i>What is your longer-term goal?</i>
 ADVOCACY DEMANDS <i>Identified key demands of your campaign?</i>

- Advocacy goal - no one with leukaemia is affected by financial issues
- Demands - expand the travel grant,

Case study 1: #LeukaemiaLevy


Key stakeholders and what they need to do for you:

- Treasury and the business department
- Partners did not appear until later

 **KEY INFLUENCERS & CHANGES WE WANT TO SEE IN THEM**

Who are the key groups or individuals you should target with your advocacy?

What are the changes you expect/like or love to see in their behaviours (these are your intended outcomes)?

 **KEY PARTNERS**

Who are the key partners, allies and networks you need to collaborate with, and what type of partnerships do you envision?

So what did we do?

A big problem with political resistance and existing policies

Something that isn't unique to leukaemia

New stakeholder to LC

No chance, right?



So what did we do?



What is success short term?

New information

New relationships

Brand awareness

Support from patients

Invitations to join with others

Learnings

Using logic and planning carefully, stops you looking stupid
Try to find commonalities across areas

BUT if people don't know who you are, don't be afraid to go big!
Will they know you exist if they miss your email?

What could we do better?

Agility and responsiveness

Sharing small wins with patients

Plotting out the full step by step process by topic

Any questions?