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Acute Leukemia Advocates Network

**HOW TO INFLUENCE POLICY  
(LOBBYING – 101)**  
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[www.acuteleuk.org](http://www.acuteleuk.org)

# Agenda




- Welcome and Introductions 5 min
- Introduction to Lobbying 10 min
- Q&A 10 min
- How to Lobby
  - Part 1 (Issue, chance of success, targets/partners) 20 mins
  - Q&A 10 mins
  - Part 2 (Tactics, evidence, pitfalls and outcomes) 20 mins
  - Q&A 10 mins
- Real Life Example or Q&A 10 mins


# INTRODUCTIONS

A decorative graphic at the bottom of the slide consists of a thick, wavy line that transitions from a deep purple on the left to a bright red on the right.


# What is Lobbying?

- Lobbying is a form of advocacy with the intention of influencing decisions made by the government or other policy makers by individuals or groups; it includes all attempts to influence legislators and officials, whether by other legislators, constituents, or organized groups.
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# Lobbying vs Campaigning

- Lobbying is a part of campaigning
  - Campaigning is wider but can assist lobbying – includes:
    - Disease awareness
    - Media activity
    - Lobbying
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# Why Lobby?

- Raise Awareness
  - Put pressure on decision makers
  - Is it worth the resources?
  - The only way to potentially make favourable changes to healthcare policy to impact large numbers of patients
  - Lobbying can also result in important changes that benefit individuals
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# Who Can lobby?


- Anyone can lobby for policy changes
    - Individuals
    - Organisations
      - Commercial
      - Charity
    - Groups of people
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# How?


- Identify your issue
  - Evaluate your chances of affecting change
  - Identify your target(s) and partners
  - Determine your approach ] (can be
  - Generate your evidence ] reversed)
  - Be solutions focussed
  - Be respectful
  - Can you be critical?
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# Identifying your issue


- What is impacting you or the patients you represent?
  - What type of issue?
    - Healthcare (outcomes, survival, cure, treatment)
    - Related non-healthcare (workforce, wider societal, age, inequalities)
  - New issue
    - What change do you want to achieve?
    - What is existing policy?
  - Ongoing/existing issue
    - Who is campaigning on the issue
    - Has any change been achieved?
      - If not, why not
      - If so, then how much has been achieved
    - Can you add weight, value?
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# Chances of affecting change

- Are you looking to change National or local policy?
  - Can your ask be linked to a healthcare or government policy priority (local will be held to this)?
    - i.e. reducing cancer deaths; better care for patients with life threatening illnesses;
  - How much support do you have?
  - How much evidence do you have?
  - Who are you lobbying?
  - Who needs to agree to the change?
  
  - Resource allocation may be a factor here
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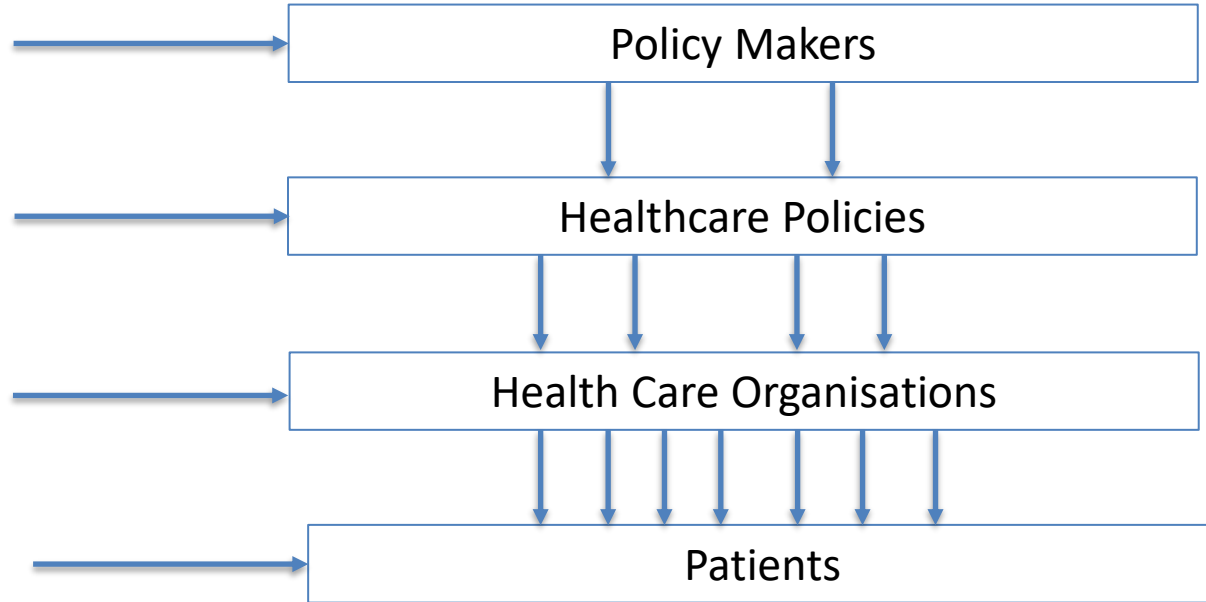
# Identify your target(s) and partners

- Who is the decision maker
  - Government or healthcare
  - What level?
- Who can influence the decision maker?
- Who can influence the influencer?
- Who has an interest and can generate awareness?
- Who else is active in this area?
  - Make a coalition

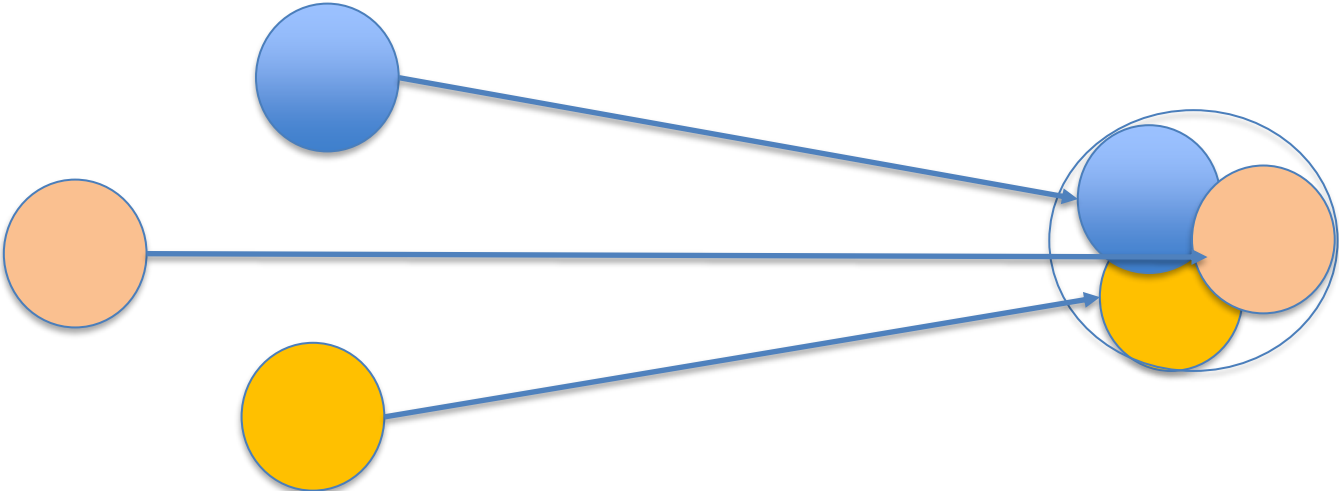


This is proper stakeholder 'mapping' – not just a list of interested people

# Decision Makers Tree



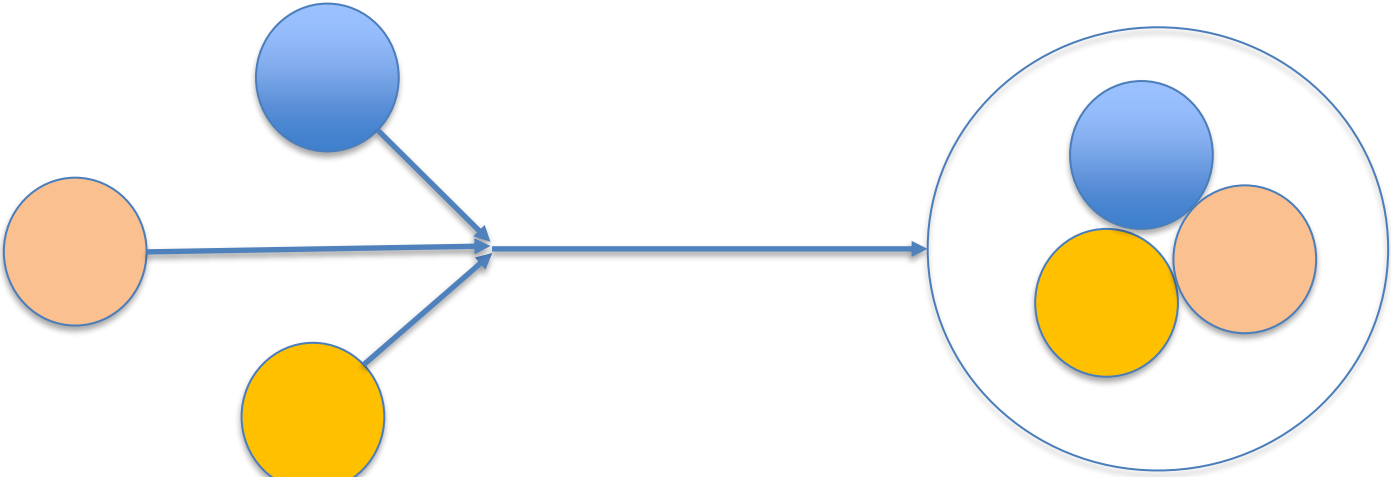
# Coalition



Lobbying in Silos




# Coalition




Lobbying in coalition



## Determine your approach (Tactics)


- Clear summary of your issue
  - Evidence and solution
  - Petitions
  - Letters
  - Parliamentary questions
  - Meetings
  - Events
  - Broader Campaign
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# Evidence of issue


- Evidence should demonstrate:
    - That the issue is ‘real’
    - The scale of the issue
      - The number of people it effects
      - The magnitude of the effect
  - Use individual stories to bring statistics to life
  - Seek the views and support of healthcare professionals
  - Consider your audience
    - National level data for policy makers
    - Local information for members of parliament
    - What is important to the decision maker/influencer?
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## Solutions with evidence

- It is critical that when you raise an issue, you have at least one solution in mind
  - Solutions should be:
    - Evidenced where at all possible
    - Supported by other stakeholders – especially healthcare professionals
  - Overall, you must attempt to:
    - Speak with gravitas and authority
    - Not just from your perspectives (partners/allies/HCPs)
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## Things to avoid

- Asking/expecting to change the world
  - Rushing
  - Not accepting stepwise change
  - It can be a long game, be patient
  - Being overly antagonistic
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# Outcomes and measurement

- Can be challenging
  - Be realistic
    - major policy change can take time
    - not all attempts to change policy will ‘land’
  - Be prepared to adapt
  - Was it me?
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# Example

- Bladder Cancer waiting times
  - Issue
    - Policy = 65 day wait from primary care referral to definitive treatment
    - Cystoscopy is considered definitive treatment for most patients
    - For patients who need further treatment, there are no applicable waiting times
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# Chance of affecting Change

- Change needed at national level
  - Waiting times set by government policy
  - Implementation by the National Health Service
  - Issue highlighted by a national patient group
    - Support would appear to be feasible
  - Evidence needs to be created
  - National Health Service is being lobbied
    - Awareness in political circles
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# Identify your target(s) and partners

- Potential partners identified
    - Professional groups – clinicians and nurses
    - Other patient groups
    - Individual high profile clinicians
    - Industry
    - Coalition formed
  - Targets identified
    - NHS commissioners (team responsible for waiting times)
    - MPs with an interest in Bladder cancer (influencers)
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# Generate Evidence

- Research on the magnitude of the issue along with qualitative evidence
  - Presented as a short infographic that:
    - Summarised the issue clearly
    - Presented figures
      - How many patients affected
      - The magnitude of the delay
      - The impact on health (real and potential)
    - Included qualitative case studies
    - Provided a solution
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## Determine your approach (Tactics)

- Two pronged approach
  - Communications to NHS team responsible for waiting time
    - Signed by coalition partners
    - Including evidence
    - Asking for meeting
  - Meetings between coalition members with interested MPs
    - Circulation of infographic
    - Parliamentary questions raised
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# Outcomes

- Several meetings with NHS team
    - Productive but slow moving (a number of team changes)
    - Pressure kept up via
      - Multiple emails signed by coalition (many going over the same ground for new incumbents)
      - Parliamentary question
  - Agreement secured from NHS to change policy on next update of policy
    - Multiple emails and meetings to check on progress and to secure timetable
    - Timeline provided but delayed by Covid-19
    - Further, follow up to ensure the promise was not forgotten (MPs and NHS)
  - Policy was updated in Autumn this year (overall the change took approximately 18-24 months to achieve)
  - Next Steps – ensure policy is acted upon at hospital level
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