

Engaging to Improve Access



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Introduction



- Remember to tailor your approach to what is appropriate for your organisation
- Be realistic – do not try to do everything
- Base this on:
 - Staff/Manpower
 - Finances
 - Remit – CLL specific? Leukaemia? Blood Cancer?
 - Existing connections?

Leukaemia CARE



- Support for anybody affected by blood cancer
- Currently 18 members of staff
- Main focus is emotional support, practical advice and information
- Campaigns and Advocacy
 - 2 members of staff
 - Engaging in campaigns, health technology appraisals, advocacy and policy work

Agenda



“Engaging with Policy makers, healthcare providers, the clinical community and industry to improve access”

1. Engaging
2. Different Stakeholders
3. Improving Access

Engaging



- What do we mean by engaging?
- Looking to shift perceptions and change behaviour/decisions
 - Working together – getting them to help you
 - But also if you disagree
 - Campaigning/Lobbying – publicly calling for change
 - Sometimes, you may be engaging with one stakeholder to help you campaign for change from another
- Key is communication – raising awareness of the issue

Who are the different players?



Important to work with all stakeholders with an interest in blood cancers. This includes:

- Policy Makers
- Payers
- Pharmaceutical Companies
- Physicians
- Patients
- Patient Organisations

Access



- What do we mean by access?
- Not just treatment, also includes:
 - Diagnosis
 - Testing
 - Information
 - Support

Preparation



Before meeting with other stakeholders, decide:

- What information is it that THEY want to know?
- What information do YOU want them to know?
- Why is your message important to them?
- What is it that they can do to help?

What do you want them to know?



- You are the voice of patients!
- You are there to represent their views and interests
- Do you have evidence/data?
- Can you provide context? Patient Stories/Quotes?
- Have a clear message - what are you trying to achieve?

What do they want to know?



- It depends:
 - If they are seeking views – there may be a formal process for patient involvement
 - However – you may be wishing to change a decision that has already been made. In this case, it will be far harder to engage them.
- Normally, they want to know:
 - Patient views - unique insight, often highlighting issues that have not otherwise been considered
 - Impact of decisions – how will it affect patients
- They may also want to know how what you are telling them will benefit them (as well as patients).



How/When to engage?

- Reactive – responding to an external change
- Proactive – you are seeking change
- Either way, seek to engage with other stakeholders as early as possible
- It is much easier to shape a decision than change one you disagree with
- And continue to engage...

Policy Makers and Payers

- Who are they?
 - Policy Makers - Government, HTA Bodies
 - Payers – National Health Service, Insurance etc.
- Collectively this group are decision makers
 - Able to make positive change for patients
- Normally – you are seeking to influence their decisions
 - Ensure the views of patients (and their families) are included when decisions that affect them are being made
- However, you may also be seeking to drive change...

Example



- Cancer Lottery Campaign:
 - Changes to the way drugs are assessed/funded in UK
 - These changes impacted on drugs for rare cancers – where there are smaller patient populations and more uncertainty in the data
 - This meant that certain drugs were available in some parts of the UK, but not in others (England/Scotland/Wales)
 - Leukaemia CARE calling on NICE/NHS England to introduce a new system for patients with rarer cancers

#CancerLottery

Pharmaceutical Companies



- Ensure that patient views are taken into account
- For example – clinical trials and patient information
- Also, can provide funding – to allow you to deliver patient support
- However, independence is crucial
 - Leukaemia CARE have a code of practice to regulate how we engage with pharmaceutical companies
 - The content of external communications are developed entirely by Leukaemia CARE.
 - Including:
 - Submissions for drug appraisals
 - Policy submissions
 - Patient information

Healthcare Professionals (HCPs)



- Often you are seeking their clinical expertise
 - Inform patient information, drug submissions etc.
 - Help draw attention to issues affecting patients
- However, you may also be trying to:
 - Share best practice – with HCPs across the country
 - Drive changes in patient care
- But, do not just engage with specialists...

Example



Blood Cancer eLearning Modules

- Developed in partnership with the Royal College of General Practitioners
- Designed to support GPs in recognising the symptoms of blood cancers

More information available is at:

<http://www.leukaemiacare.org.uk/GP-training>

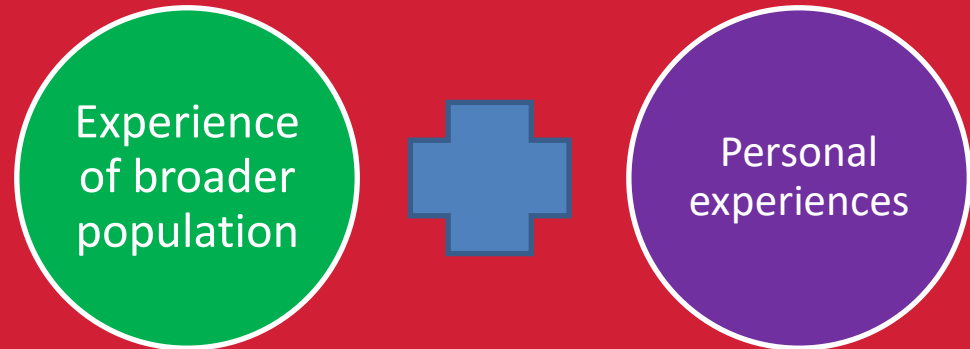
The screenshot shows a webpage for an eLearning module. At the top left is the Royal College of General Practitioners (RCGP) logo. The title 'Haematological malignancies in the UK' is in blue. Below the title is a small image of a blood smear. To the right of the image, the following information is listed: 'Est. Time: 30 mins', 'Author: Dr Khyati Bakhai', and 'Curriculum Field: 3.04 Care of children and young people, 3.05 Care of older adults'. A 'Description' section follows, explaining the challenges of early detection and the session's focus on UK epidemiology and patient experience. A 'Learning Objectives' section lists four bullet points: recognizing symptom clusters, understanding primary care investigations, being aware of peak age ranges, and appreciating patient experience. The RCGP logo and 'Leukaemia CARE' text are visible at the bottom left of the page content. A dark blue sidebar on the right contains navigation icons and the page number '1/36'.

Patients



Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life

- Different from other players
- Here your focus is on gathering information to help you engage with other stakeholders
- Patient Views:
 - Experience of broader population
 - Personal experiences
- Individuals = emotive
- Collective = evidence
- But also – it is important to keep them updated
 - Let them know about upcoming campaigns/projects
 - But also success of past projects and how they helped



Sourcing Patient Views

It may already be available:

- Social Media/Forums
- Published literature

You can go out and gather:

- One-to-one discussions (e.g. telephone helplines)
- Surveys
- Focus Groups
- Use your networks – other charities? Medical Advisors

Example



Leukaemia CARE Cancer Patient Experience Survey

- Follow up to NHS England's annual Cancer Patient Experience Survey (CPES)
- To drive improvements in the care of patients
- Survey 1000+ responses from blood cancer patients
- Covers diagnosis, treatment, information, support, testing and monitoring, impact of living with a blood cancer and after treatment
- Ongoing, available at:
<http://www.myonlinesurvey.co.uk/LE16ANON/>

Other Patient Groups



- Individually or Coalition Groups
- How can you help?
 - Share information
 - Develop best practice
 - Work together on key issues (increase your reach)
 - E.g. joint letters/campaigns?
 - Joint meetings – key speakers more likely to attend one large meeting than multiple smaller ones

Example – Patient Organisations



Collaboration between Leukaemia CARE and CLL Support Association:

- Health Technology Appraisals – Joint Submissions
- Joint support group for patients in Cardiff with chronic blood cancer
- Sharing each others services and projects/initiatives



Example - Coalition Groups

- Numerous groups can be helpful.
- Working together where there is common ground to address a specific issue:

UK

- Blood Cancer - Blood Cancers Alliance
- Rare Cancer - Cancer 52
- Cancer - Cancer Campaigning Group
- Access - Access to Cancer Medicines Coalition

Europe/Worldwide

- Such as CLL/MPN Advocates Networks...

Lessons Learned



1. Know your message – what do you want to achieve?
2. Patient views – individually AND collectively
3. Do you have evidence/data – e.g. surveys?
4. Work together – with all other stakeholders
5. Keep your membership informed – they can help advocate and raise awareness to provide pressure.



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ANY QUESTIONS?

