

THE INFORMED PATIENTS TOOLKIT



RARER
cancers
FOUNDATION

Registered Charity No. 1109213

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Introduction

The Rarer Cancers Foundation (RCF) has a strong heritage of campaigning for better treatment and services for people with rarer cancers.

Our campaigning activities have led to the introduction of the Cancer Drugs Fund (CDF), a radiotherapy innovation fund and measures to improve symptom awareness of rarer cancers.

We know that by involving you in what we do, we can have a greater impact because it is your experiences that will make a difference and resonate with the people who are making decisions about rarer cancer services.

New health services are based on the principle of 'no decision about me, without me' – patients have an even greater right to be at the heart of decisions about the design of services and their own care.

What is a rarer cancer?

The RCF defines rarer cancers as those that are less common or officially classified as rare. This definition includes:

- *Less common cancers which includes all cancers except the 'big four' of lung, breast, bowel and prostate cancer*
- *Rare cancers where there are fewer than 6 cases per 100,000 population*

Although around half of cancer patients in England have a rarer form of cancer, outcomes and experiences have generally been poorer among this group than for those patients with more common forms of cancer. This document is designed to give you background information to help you to campaign for change.

It includes:

- *Frequently asked questions on the new health care system structures*
- *A summary of some of the challenges for patients with rarer cancers*
- *How to campaign for access to cancer drugs*
- *How you can campaign to improve rarer cancer services and give a voice to rarer cancer patients*
- *Useful links to websites that you may need to use*

If you have any questions about the information in this document, please contact the RCF on mytoolkit@rarercancers.org.uk

Rare cancers
where there are
fewer than
**6 CASES PER
100,000**
population

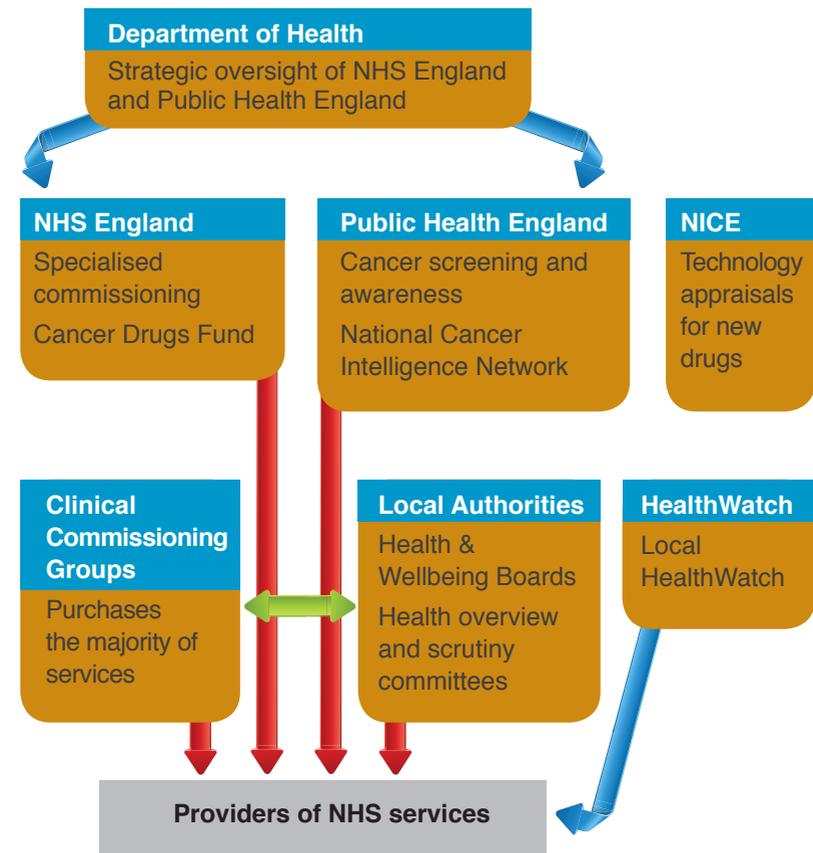
About the new health services

In April 2013, a new system for health and social care services was officially introduced in England.

A number of new organisations and structures have been established which are designed to ensure that clinicians have a greater input in the way that services are managed.

In this new system, there should not be significant changes in the way that rarer cancer patients receive care and support; however, there should be a greater emphasis on patient choice and improving patient outcomes.

Diagram of new health service structures



Key

- ▬ - Organisation
- ▬ - Relevant function
- ➔ - Buying services
- ➔ - Coordination via health and wellbeing boards
- ➔ - Accountability, operating frameworks and patient involvement

These frequently asked questions set out background information on some of the new bodies that you may come across when you campaign for better services and access to treatments.

It also includes information on the remit of existing organisations, whose roles have changed as part of the reforms. Links to further information about all of these bodies are included in Annex 1.

What is the Department of Health (DH)?

The DH provides strategic oversight over health and social care in England through national policies and legislation. It helps to shape the long-term vision and ambition within health and social care services. It helps to shape the priorities of NHS England through a document called The Mandate.

The DH is accountable to Parliament for health and social care in England but it is not responsible for the day-to-day management of the NHS.

What is NHS England?

NHS England is an independent body that is responsible for the day-to-day running of the NHS. It is in charge of overseeing and driving up quality among local clinical commissioning groups (CCGs). It also has responsibility for purchasing (or commissioning) some services such as primary care and specialised services.

Less common cancers include **ALL CANCERS** except lung, breast, bowel and prostate cancer

What are the regional and local area teams of NHS England?

There are four regional offices of NHS England, supported by 27 area teams representing NHS England at a local level. Ten of the local area teams will have responsibility for the implementation of specialised commissioning in their area. Four of the area teams (one in each region) will manage the operation of the Cancer Drugs Fund.

What is Public Health England (PHE)?

PHE is in charge of improving outcomes in public health across England. It has a wide range of responsibilities, including encouraging a more pro-active approach from Government, organisations and individuals to improve public health in England. Of particular relevance to cancer, it is responsible for managing screening programmes and awareness campaigns. PHE also oversees the collection and publication of data through the National Cancer Intelligence Network.

What is a Clinical Commissioning Group (CCG)?

A CCG is a clinically-led organisation that has the legal responsibility for planning and purchasing the majority of NHS services for their local population. They are led by GPs, with input from other clinicians and health managers called commissioners. There are 212 CCGs across England. In the 'old' NHS, this role was carried out by primary care trusts (PCTs), which no longer exist. There should be patient representation on these CCG boards.

What is specialised commissioning?

Specialised commissioning is the purchasing of NHS services that are classified as specialised – this means that they are delivered in relatively few centres, or affect only a limited number of people. These services are commissioned by NHS England. Certain areas of care for rarer cancers patients fall under this system, including chemotherapy drugs and some radiotherapy.

What is a Commissioning Support Unit (CSU)?

There are 19 CSUs which are part of NHS England. Their role is to support CCGs and NHS England in transformational commissioning functions (for example, when a service is being redesigned). They will also support the day to day commissioning functions, such as contract negotiation and information and risk analysis. CCGs will be given the option to choose who provides their commissioning support. This could be from one of these 19 central CSUs or from another provider of these services.

What is a Strategic Clinical Network (SCN)?

SCNs are the successors to cancer networks, bringing together expertise from all of the previous disease specific networks. The new SCNs are designed to provide expert advice to CCGs to ensure that decisions about service design and commissioning are informed by relevant clinical expertise.

What is a Health and Wellbeing Board (HWB)?

HWBs are local groups that are responsible for ensuring coordination in services on a local level. They are managed by local authorities (elected Councils) and are meant to ensure joined-up working across public health, NHS and social care services. HWBs are responsible for assessing the health needs of local populations and ensuring that a strategy is in place to address these needs. There should be patient representation on HWBs.

What is a health Overview and Scrutiny Committee?

Each local authority has in place a health overview and scrutiny committee. This is made up of councillors that are not on that authority's Executive Committee. Its members are responsible for scrutinising the delivery of health and social care programmes on a local level, ie your local NHS hospitals and community care services.

What is HealthWatch?

HealthWatch England is a new consumer champion that represents the views of patients. It sits within the Care Quality Commission (CQC), the national body which is responsible for ensuring quality care across the NHS and social care. It is comprised of 12 committee members who work with 152 local HealthWatch organisations and other partners to build a national picture of what matters most to people who are accessing health and social care services.

On a local level, local HealthWatch replaces Local Involvement in Health Networks (LINKs) and is meant to promote choice and provide advocacy for patients through the complaints process. Local HealthWatch bodies are designed to ensure that complaints on a local level can feed into national inspections by the CQC.

What is the National Institute for Health and Care Excellence (NICE)?

NICE has a central role in appraising both the clinical and cost-effectiveness of new treatments and establishing whether they will be routinely funded by the NHS through the technology appraisal system. Patients and their representatives have a role in the technology appraisal process, which is important in order to ensure that the decision making Committee understands the particular impact of a condition and the benefit of a specific treatment. It has also been given responsibility for developing quality standards, markers of high-quality, cost-effective patient care that are meant to inform the design and purchasing of services across health and social care.

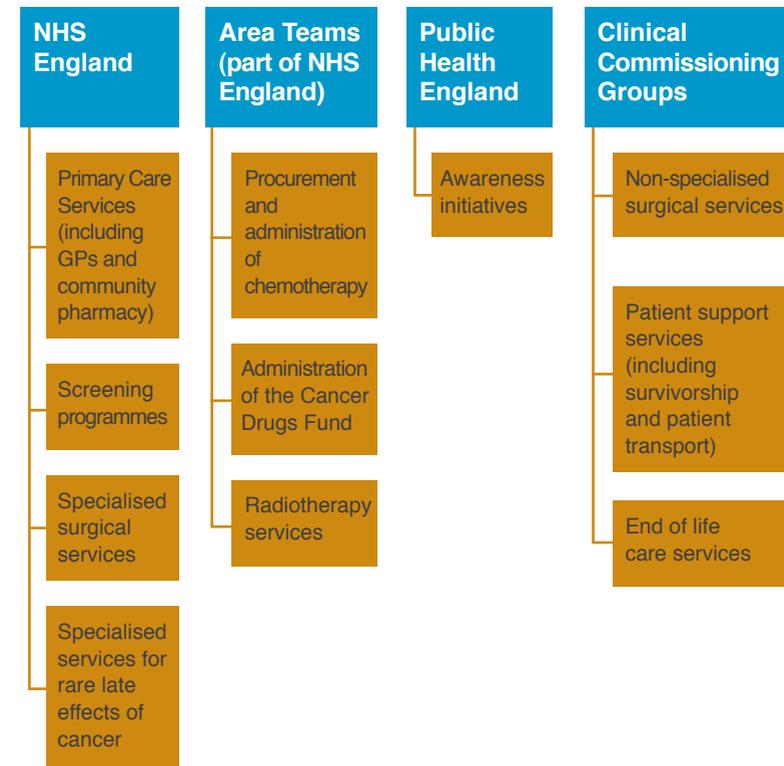
What is the NHS Constitution?

The NHS Constitution establishes the principles and values of the NHS in England. It sets out the rights that staff, patients and the public can expect from the NHS and pledges what the NHS is committed to achieve. It also sets out responsibilities that individuals (public, patients and staff) owe to one another to ensure that the NHS operates fairly and effectively. The Secretary of State for Health, all NHS bodies, private and voluntary sector providers supplying NHS services, and local authorities in the exercise of their public health functions are required by law to take account of the NHS Constitution in their decisions and actions.

Who commissions services for cancer patients?

Commissioning is the purchasing and planning of health care services for a population. With regard to cancer commissioning of some services this is done on an England wide basis, whereas some other services are commissioned by local organisations.

Responsibility for commissioning cancer services



Challenges for rarer cancer patients

More than 50% of all cancer cases are classified as 'rarer', ie they fall outside the more common and highly publicised cancers such as bowel, breast, lung and prostate. In 2010 that meant that over 125,000 people were diagnosed with a rarer cancer in England.

Although services and outcomes for patients with rarer cancers have improved, there is still much to do. The National Cancer Patient Experience Survey, a national survey on the experiences of patients with cancer, found that patients with rarer cancers often have poorer outcomes and have reported worse experience than patients with more common forms of cancer.

This section summarises some of the challenges for patients with rarer cancers. In addition to your own experiences, you may wish to raise some of these issues when campaigning for change.

Early diagnosis

Diagnosing cancer earlier means that there are more treatment options available to patients and a greater chance of long-term survival than when cancers are diagnosed late. There are particular issues for patients with rarer cancers:

- **Poor symptoms awareness:** *almost one third of patients surveyed by the RCF waited more than three months between experiencing symptoms and seeking medical help and nearly a third were reassured by their GP that there was no cause for concern when they first presented with symptoms*
- **Late diagnosis:** *more than one quarter of patients with rarer cancers are diagnosed following an emergency – suggesting that too many patients are being diagnosed when their cancer is already at an advanced stage*
- **Poor experience:** *over one third of patients rated their experience of receiving a diagnosis either poor or very poor in the RCF survey 'Primary Cause' (February 2011)*
- **Poor support:** *Rarer cancer patients are often left in limbo without support or specialist care while local clinicians and nurses search for specialists with experience of particular rare cancers*

National measures such as awareness campaigns and moves to encourage GPs to take a different approach to referrals to make this quicker, ie to refer earlier, are both issues that you may wish to raise when talking about improving early diagnosis.

 **125000**
PEOPLE DIAGNOSED WITH
A RARER CANCER IN 2010

Access to treatment

The RCF believes that all patients should get access to the drugs that their clinicians wish to prescribe, and has long campaigned to make this a reality. For patients with rarer cancers, small patient numbers often mean that there is limited evidence and data. This means that accepted standard policies which govern whether drugs are made available or not do not always work for rare cancer treatments.

- **Orphan drugs:** *orphan drugs are treatments that have been developed that affect only a handful of people – less than 5 cases per 10,000 of the population. Due to the very small patient numbers involved, these treatments can be expensive so they do not always meet cost-effective requirements set out by NICE to be routinely funded on the NHS*
- **Off-label treatment:** *for some rare cancers, there may be no licensed treatments available, due to the difficulties in conducting large scale randomised trials in extremely rare conditions. There may, however, be treatments which have been licensed for more common forms of cancer which develop in a similar way to the rare cancer in question. This is called off-label treatment. For these treatments, there is likely to be less evidence about effectiveness and safety but the medicine in question will have been tested extensively in patients with more common, but similar types of cancer. Clinicians will use their experience and expertise to judge whether a particular treatment for one type of cancer may be beneficial in treating a rarer cancer patient with a different type of cancer*
- **Radiotherapy:** *accessing special radiotherapy techniques can be difficult if funding for machinery or expert staff are not in place. There have been announcements to improve access to radiotherapy techniques but it is not yet known what impact this will have on access to these treatments*

The RCF successfully campaigned for a radiotherapy innovation fund to increase availability of life-saving advanced radiotherapy techniques on the NHS and a Cancer Drugs Fund (CDF) to allow routine access on the NHS to cancer drugs that clinicians wish to prescribe.

A new pricing mechanism (value based pricing) for new drugs may be introduced in 2014. At present it is unclear how this will impact on access to cancer treatments for patients. The RCF is involved in discussions about funding for cancer drugs and there is further information and updates on the RCF website about this issue.

Access to advice and support

Being diagnosed with, and receiving treatment for cancer can be traumatic for both the person affected and their families. Advice and support is an important mechanism to help people to come to terms with a cancer diagnosis and feel able to tackle it. There are some areas where rarer cancers patients are disadvantaged:

- **Clinical nurse specialists (CNSs):** *CNSs have been proven to have a positive impact on patient outcomes and experience but patients with rarer cancers have less access to CNSs than those with common cancers. The latest Cancer Patient Experience Survey (CPES) found that while 93% of breast cancer patients have a named CNS in charge of their care, just 75% of urological cancer patients, 79% of sarcoma and 83% of head and neck cancer patients have access to a named CNS. Therefore for the rarer cancers patients it is unlikely that they will have access to a named CNS*
- **Written information:** *Due to the number of different types of cancer, there is less written information available for patients with rarer cancers than for those with the more common forms of cancer. Written information is important in allowing people to understand about their condition and treatment options.*

The RCF campaigns for better access to CNSs for rarer cancer patients but this is still an area that requires attention on both a local and national level. We also offer a range of support services for patients which you are welcome to use.

What support does the RCF currently offer?

Rarer Cancers Forum

Our rarer cancers online forum is the place you can turn to find friendship and read the experiences of other rarer cancer patients and carers who understand exactly how you feel no matter what type of cancer or how rare.

We want our forum to be a place where patients and carers can come together and ask questions, share their experiences, exchange information and generally support each other. Our aim is to make sure you get the best support for your particular type of cancer and to help bridge the gap between the medical expertise of your hospital team and day-to-day reality of coping with a diagnosis of a rare or less common cancer.

The Rarer Cancers Forum can be found here:
www.rarercancers.org.uk/forum/

RCF Helpline

The RCF Patient Support Team manages the RCF helpline and each representative has firsthand experience of cancer. The helpline is there to support and help patients and carers through their cancer journey.

The helpline number is 0800 334 5551.

“Here to help” every weekday 10am – 4pm

or you can leave a message outside these times and we will return your call.

Written information

Over the years the RCF has developed information about rarer forms of cancer and we are currently working with the Royal Marsden cancer centre to develop a comprehensive library of factsheets on rarer cancers. These will be freely available from the RCF website later this year and will cover around 180 different types of cancer.



**OF ALL CANCER CASES ARE
CLASSIFIED AS 'RARER'**

How to campaign for access to cancer drugs

The system for making drugs available in England is relatively complex and has a number of steps which are described here for your information.



How do clinical trials work?

Clinical trials are medical research studies which involve people. Clinical trials look at new treatments or procedures and are designed to ascertain if a treatment is safe, has side effects or works better than a currently used treatment.

There are four phases of clinical trials:

- **Phase I** – checks if a treatment is safe or has any harmful effects. Establishes the best dose to use
- **Phase II** – looks at how well a treatment works. It is tested in a moderate number of patients to see how effective it is and to identify side effects
- **Phase III** – tests the treatment in a larger group of patients and compares the new treatment against existing standard treatment
- **Phase IV** – this takes place after a license has been granted and involves conducting studies to monitor the effects of the treatment in routine clinical practice

Your clinician should inform you if there are any relevant ongoing trials for you.

How do medicines receive a license?

Once a treatment has been proven to be effective and safe through clinical trials it will receive a license from either the European Medicines Agency (EMA) which grants licenses for medicines in the EU, or the Medicines and Healthcare products Regulatory Authority (MHRA) which grants licenses for medicines only in the UK. Normally the pharmaceutical company which makes a drug will submit an application to the MHRA to receive a license. It is only after a medicine receives its license that it can be sold within the UK.

How do drug companies apply for routine funding?

NICE is an independent organisation which provides national guidance on health and social care issues. One of its roles is to assess new drugs to work out whether they are cost-effective. NICE takes forward an appraisal when this is formally requested by the Department of Health. There are a number of reasons why the Department of Health may refer a medicine to NICE for assessment, including inappropriate variation in access across the country, if the treatment is likely to have a significant health benefit or impact on NHS resources. These assessments are on drugs that have already been licensed for use as safe by the MHRA or the EMA.

Pharmaceutical companies will need to make an application to NICE providing information about the clinical trials for a particular treatment and the cost of that treatment. External organisations, such as NHS commissioners, charities and organisations representing professionals (ie clinicians and nurses) are invited to be consultees to support the appraisal process. An independent academic institution will also undertake a health economic assessment of the evidence describing the cost effectiveness of a treatment to the NHS.

This information is used to develop an appraisal consultation document (ACD). Once consultation responses have been made to the ACD, NICE will publish a final appraisal determination (FAD) which states whether a treatment is recommended or not recommended for routine funding in the NHS. A consultee (pharmaceutical company, clinician, professional body or patient group) can appeal at this point but the FAD is normally an indication of the final decision.

If NICE recommends a treatment, the NHS has three months to make that drug available to the group of patients it is licensed for.

Some drugs will be made available on the NHS without a NICE technology appraisal although these tend to be treatments which are not expensive and form a routine part of day-to-day care. These drugs are normally added to the formulary which is the official list of treatments that should be funded by the local NHS.

When are drugs not routinely funded by the NHS?

There are a number of instances when drugs are not routinely available, including where drugs:

- *Have been licensed but have not yet been assessed by NICE (this could be when a drug is still going through the NICE process or because a pharmaceutical company decides not to submit evidence to NICE)*
- *Have not been recommended by NICE, often on the basis of cost-effectiveness*
- *Are used outside their licensed indication, known as 'off-label' usage*

How can you get access to treatments that are not routinely available on the NHS?

There are a number of ways that you can access treatments that are not routinely available on the NHS, including:

- **Cancer Drugs Fund (CDF):** *an annual fund which is designed to ensure that cancer patients have access to the treatments that their clinicians wish to prescribe but that are not routinely available on the NHS*
- **Individual Cancer Drugs Fund Requests (ICDFRs):** *an individual application for a drug that is not routinely available via the Cancer Drugs Fund*

- **Clinical trials:** *clinicians will be able to advise if there are any ongoing clinical trials for a particular drug or patient type. Participation in trials means that you can get access to drugs which may not be licensed yet*
- **Private:** *patients may wish to pay for a drug privately although this is only possible for NHS patients if all other avenues (CDF, ICDFR, appeals) to receive funding have been exhausted*
- **Third party access:** *ask your clinician about other routes*

This document outlines the CDF application process in more detail. If you would like further information on clinical trials or paying for treatment privately then please contact us for more information.

How does the CDF process work?

The CDF will be in operation until at least the end of March 2014 and £200 million will be available to fund cancer drugs that are not routinely available.

The Fund is managed by NHS England with four regional area teams holding responsibility for the operation of the Fund at a local level:

Regional team	North of England	Midlands and East	South of England	London
Local area team	Cumbria, Northumberland, Tyne and Wear	Leicestershire and Lincolnshire	Wessex	London

Each local area team will have a clinically-led panel which is comprised of oncologists, haematology-oncologists, pharmacists and specialists in public health. There is no patient involvement in the CDF process or policy making, and neither patients nor patient advocates have an opportunity to engage in the process.

Your clinician will make the application to the CDF on your behalf. Your application will be made to the area team where you will be treated, rather than where you live.

There are ways that a clinician can apply for funding through the CDF:

- **National CDF cohort policy list:** *a clinician will submit an application setting out why you are eligible to receive a particular treatment. Where the specified requirements are met, funding will be released and a clinician will be able to commence delivery of treatment. The decision on funding treatment on the national list should be made within two working days.*
- **ICDFRs:** *Regional clinically-led panels will review applications from your clinician for cancer drugs which are not included on the national list. Prior to making an application, the request must be supported by your hospital's chemotherapy lead. The local area team will be responsible for processing the applications on behalf of NHS England, in line with nationally agreed guidance and standard operating procedures.*

The CDF panel making the decision about your treatment will include oncologists, pharmacists, public health representatives, NHS managers and patient or lay representatives. The decision on applications to the ICDRF process should be made within ten working days.

If the decision is made not to fund a treatment, the clinically-led panels must explain the reasons for the refusal and make clear that there is an opportunity to re-review the application if new evidence is available.

Links to the CDF guidance is available in Annex 1.

What can I do if I am refused access through the CDF?

It is possible to appeal a decision but only on the basis of the decision-making process, not on the merits of a particular application. An appeal must be made within 20 working days of the application decision and must be submitted by your clinician. These are tight timelines so you will need to engage regularly with your clinician to ensure that they are aware that you wish them to make the appeal application and how long you think it will take to assemble the supporting information.

In order to make an appeal application, it will be very useful for your clinician to have available a range of information including:

- *Letter of refusal detailing reasons for refusal in writing*
- *Copy of all the documents that the CDF panel had in front of them when discussing the case, including the original application form*
- *Names of any experts or individuals they contacted to provide additional information*
- *Names and qualifications of the CDF panel members who made the decision to refuse*
- *Minutes from the meeting where it was decided to refuse the application*
- *Timeline of events, including when the application was made, when it was considered by the panel and when the final decision was made*

You can help your clinician obtain this information, and some of this information will already be available and may have been sent to him/her. However, you may need to contact the regional area team panel to ask them for some of the information. Once you have this information, your clinician can submit the appeal on your behalf.

A review panel will either uphold the decision of the clinical panel or it will instruct the panel to reconsider the application. Once the appeal has been submitted, a response should be received within five days.

The RCF has experience of supporting patients and carers who are appealing funding decisions so please contact us for more information. Outside the formal appeal process, there are other activities that you can do to campaign for access to treatments. We outline some of these in more detail in the next section.

How can you influence policy to help rarer cancer patients?

There are many activities that you can do to help to ensure that there is a rarer cancers voice in policy decisions. We would divide these into two types of campaigning:

- *Proactive: where you engage with local people, organisations and the media on a particular issue or issues to call for change and get your own campaign message on the agenda*
- *Reactive: where you respond to a request for information or sit on an advisory group for a particular organisation*



Proactive campaigning

This section summarises some of the proactive campaigning opportunities and ways that involving other people or organisations can help to move your issues further up the agenda. We have identified four activities for you to consider:

1. *Contacting your local elected representatives (including MPs and local councillors)*
2. *Engaging with the media*
3. *Connecting with other patients on the RCF Forum*
4. *Taking concerns to local HealthWatch*

Why is it good to involve your local MP?

MPs are your elected representatives in the UK Parliament in Westminster and in your constituency so they are well placed to take on board your issues and take steps to tackle it through:

- *Contacting your local NHS or local authority on a particular issue*
- *Liaising with the Government on your behalf about national policies that may impact on your experience and care*
- *Raising the issue up the agenda through parliamentary scrutiny or the local media*

You can find out what your MP has been saying on health issues by looking them up on the following website:

www.theyworkforyou.com

Why is it good to involve your local councillors?

Local councils have been given a specific responsibility to ensure coordination across health, public health and social services in the new health care system through health and wellbeing boards. They also have responsibility for public health including local awareness campaigns. If you want to raise particular issues around early diagnosis or where you have not received joined-up care, your local councillor may be able to help. Your councillor may also sit, or have colleagues who sit, on the health overview and scrutiny committee so will have oversight over local health issues.

How can you get your local elected representatives involved?

There are a number of ways in which you can ask your local elected representatives to get involved and raise the profile of rarer cancers. Some MPs and councillors are already active in campaigning on rarer cancers but others are unaware of the impact of the disease on patients, families and the NHS and the particular challenges for these patients.

To get your local elected representatives involved, you could:

- *Request a meeting at your local MP's constituency surgery to speak to your MP face to face*
- *Request a meeting with your local councillor to speak to them about your experiences*
- *Write a letter or email to your local representative about your personal experience of living with cancer and ask them to take action to improve services in your area*

How can you contact your local MP?

If you are unsure who your MP is, then you can find out by typing your postcode into the website **www.theyworkforyou.com** You can then either write to your MP requesting a meeting or telephone their office:

- **Write to them:** *you can write a letter or email setting out that you would like to meet your MP, summarise your experiences and what issues you would like to talk about (you may wish to cover some of the topics we have summarised above).*
 - *All MPs can be contacted at the House of Commons. The address to write to is:

House of Commons, London SW1A 0AA*
 - *MP email addresses are available on the parliament website at the following link:
<http://www.parliament.uk/mps-lords-and-offices/mps/>*
- **Call them:** *you can call the main House of Commons switchboard on 020 7219 3000 and ask to speak to your MP's office once you have found out who he or she is by following the step above. Let the MP's office know that you want to attend the MP's constituency surgery to talk about your experiences.*

1. How can you contact your local councillor?

You can find out who your local councillors are on the website: **www.writetothem.com** by typing your postcode. This website lets you email your councillor directly but if you would prefer to write a letter, telephone your councillor or send a separate email, you can find all the contact details on your local council's website.

What should you expect when you contact your elected representatives?

Most MPs have an office in their constituency that can help with arranging a meeting or advising you when and where your MP's next 'surgery' will be held (usually weekly, on a Friday). Your MP won't expect you to know about the detail of health policy issues on rarer cancers, but will want to hear about your experiences, how you have been affected and what they can do to help.

The process for meeting your local councillors will vary between individuals. Some councillors will be open to meeting with you but some will prefer to respond via email or letter. If a councillor chooses not to meet you, it does not mean that they are not willing to take forward your issue. In all cases, keep copies of letters or emails. Do follow-up letters asking for answers to questions you have raised.

What should you talk to your elected representatives about?

Your MP will want to hear about your experience of living with cancer, your treatment and care. Is there anything that the local NHS could change to improve your experience and that of other people with a rarer cancer in the future?

We have set out some of the challenges for rarer cancers patients above which you may wish to consider when you meet your MP.

The new health structures give local authorities and local councillors a greater say in the operation of health services as they are responsible for running local health and wellbeing boards which are designed to ensure coordination of health and social care services on a local level.

How can you encourage your local representative to take action?

Try to establish a list of actions in advance that you would like your elected representative to take forward. We have identified some suggested actions here that you could suggest:

Actions for your MP

- *Write to the NHS England regional area team*
- *Write to the local Health and Wellbeing Board*
- *Write to the Secretary of State for Health or a Health Minister*
- *Raise awareness of rarer cancers on their website or through the local media*
- *Table parliamentary questions in Westminster about rarer cancers*

Further information about these bodies and how to contact them is included in Annex 1.

Actions for your local councillor

- *Speak to the local Health and Wellbeing Board to get rarer cancers on the agenda*
- *Write to the local CCG*
- *Raise awareness of rarer cancers on their website or through the local media*

If you need any help in contacting your MP, please contact the RCF on mytoolkit@rarercancers.org.uk

2. Contacting the local media

Why is it good to use the local media?

Local media coverage can help to give your campaign a boost and get your messages across to a much wider audience than you could on your own. By getting your campaign or story in the media, it can help to encourage local elected representatives to take action and it may also lead to local health services taking action to improve services and outcomes.

How can you get your story or campaign in the media?

There are a number of ways that you can get your story or campaign heard:

- **Be a case study:** *the RCF is always looking for patient case studies to support our national media stories. If you are interested in participating in a patient case study please email mytoolkit@rarercancers.org.uk*
- **Send a press release to your local newspaper:** *local newspapers are looking for stories about local issues. You can send a press release to your local media by sending it to the news desk email address that will be on your local newspaper's website*
- **Write a letter to your local newspaper:** *writing a letter on your own or with a group of other patients or carers can be another way to get your issue on the agenda. Most newspapers have a letters' email address where you can send your letter directly*
- **Work with your elected representatives to get coverage:** *MPs and councillors will be keen to show that they are supporting local issues in the media. These individuals normally have good links with the local media so you may wish to encourage them to contact the local media about your campaign*

3. Connecting with other patients on the RCF Forum

The RCF Forum is designed to provide an opportunity for you to make contact with other people who are going through the same experiences as you. To date, we have a network of over 400 patients and carers on our Forum. By working together with other patients, you may be able to undertake local campaigns together. By working together we can achieve more.

The RCF would like to support you in undertaking this kind of campaign locally, so please contact us on mytoolkit@rarercancers.org.uk if you have an idea about how you might want to campaign with other Forum members.

4. Taking concerns to local HealthWatch

You can also speak to your local HealthWatch about concerns you may have about your care. These bodies are in place to help local people to get the best out of their local health and social care services so are in a good position to help you to take forward your issue on a local level.



Reactive campaigning

This section summarises the reactive opportunities for you to get involved with:

- **Being a patient or lay representative on health organisations or groups:** *'No decision about me, without me' is a key element of the new health services and there is a duty on statutory health bodies to ensure that patients, carers and the public can get involved in local decisions about care.*

Organisations that may be looking to involve you in regular meetings and work programmes on a local level include the following.

- CCGs
- Health and wellbeing boards (hosted by local authorities)
- Local HealthWatch

Links to further information about your local organisations are included in Annex 1.

There may also be opportunities to engage in the activities of strategic clinical cancer networks, although at present there is limited information about how these will operate in the new NHS.

Occasionally, national engagement opportunities arise and we will be in contact with you to see if you are interested in getting involved when appropriate.

- **Responding to consultations:** *a consultation is where an organisation seeks the views of the public and interested people or organisations on a particular policy or idea. These consultations can last for anything from four weeks to three months. The RCF often responds to consultations that are likely to have an impact on services and experience for patients with rarer cancers and we may like to contact you to ask for your views on particular issues to help inform our responses.*

Preparing for reactive campaigning opportunities

The main thing to note is that, if you are the patient or lay representative on a panel, you have been invited as a representative of people in your local area or your patient community. It is not simply an opportunity for you to talk about your poor (or good) experiences on a local level – although these are the stories that will bring issues to life and help to inform local decision-makers on what works well and not so well on a local level.

If you take on this role, meetings that you are invited to attend will have a set agenda. Although, your contribution will be most valuable when you apply your experiences to the issues up for discussion, the meeting will not just be about your personal situation. This means that if a health and wellbeing board is discussing how well local services work together, your experiences of being referred from primary to secondary care might be insightful to them in making things better in the future.

Try to think about suggestions of what would have made your care better as well.

Although some meeting participants will be welcoming when you attend, you may find others are more 'closed' to patient contributions. The NHS is meant to be patient centred - your experience is important if services are to be improved. Try to be confident about why you are there and speak out about issues which concern you. When those around the table realise that what you have to say will help them to make better decisions, they should sit up and listen. Make sure your contributions are minuted and actioned .

Annex 1 – Useful Links

The NHS, health and social care services

Department of Health –
www.gov.uk/government/organisations/department-of-health

NHS England – www.england.nhs.uk/

Appointments to local area teams –
www.england.nhs.uk/appointments/lat/

Appointments to regional offices of NHS England –
www.england.nhs.uk/appointments/regional/

Public Health England –
www.gov.uk/government/organisations/public-health-england

Which is your clinical commissioning group? –
www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1

Which is your local health and wellbeing board? –
www.local.direct.gov.uk/LDGRRedirect/Start.do?mode=1

Specialised commissioning –
www.england.nhs.uk/resources/spec-comm-resources/

National Institute for Health and Care Excellence –
www.nice.org.uk/

HealthWatch – www.healthwatch.co.uk/

Which is your local HealthWatch? –
www.healthwatch.co.uk/find-local-healthwatch?address=

NHS Constitution –
www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf

Cancer Drugs Fund

Cancer drugs available via baseline commissioning (April 2013) –
www.rarercancers.org.uk/images/stories/news/0413/cdf_letter_to_at_re_4_drugs_15.4.13.pdf

Cancer Drugs Fund policy –
www.england.nhs.uk/wp-content/uploads/2013/03/cdf-sop.pdf

Cancer Drugs Fund national list –
<http://www.england.nhs.uk/ourwork/cdf/>

Radiotherapy

Radiotherapy Clinical Reference Group –
www.england.nhs.uk/npc-crg/group-b/b01/



RARERcancers
FOUNDATION

the voice of rarer cancers

The Rarer Cancers Foundation offers advice and information to individuals with rare and less common cancers or to their families and friends.

The charity facilitates supportive networking, raises awareness of rarer and less common cancers and works to ensure that people with rarer cancers have access to the best possible services



Helpline 0800 334 5551



General Enquiries 0208 692 2910



helpline@rarercancers.org.uk



www.rarercancers.org.uk

Registered Charity No. 1109213

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