



“Less is more! The way forward.”

**Simon Davies , Chair of Cancer 52 –
representing 57 cancer charities that
focus on rare and less common cancers**

Diagnosis impact



Now what?

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- Where do I go?
- Who do I trust?
- What do I ask?



Which Advisor?

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Early Diagnosis

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- What are the diagnostic and referral performance of GP's and hospitals?
- What are the range of specialists and diagnostic services provided by GP's?
- What public health and education services are delivered by GP's?
- What technology and diagnostic aids are used by GP's?
- The above by eg. size of practice; location; socio economic factors; ethnic range of patients etc

What treatment?

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Treatment Options

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- What are my treatment options?
- What are the outcomes of treatments for survival and quality of life?
- Can I go private and will this impact on my NHS status?
- How do I get a second opinion and how will this request be perceived?
- What treatments/services will my commissioners pay for compared to others?

Best Value?

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Optimum Treatment

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- Where are the centres of excellence?
- How many patients with my cancer do they treat?
- Which hospitals have a specialist MDT and CNS for my cancer, including sub sets?
- Is the hospital compliant with NICE Guidance and NCAT Peer Review?
- Is there measurement of implementation of NICE?
- What is the performance of each specialist and MDT?

What's new?

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New Treatments

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- Are there clinical trials and are there any barriers to me being entered?
- What new treatments exist and what is my right of access to them?
- Can successful drugs in common cancers be trialled with my rare cancer?

Which information?

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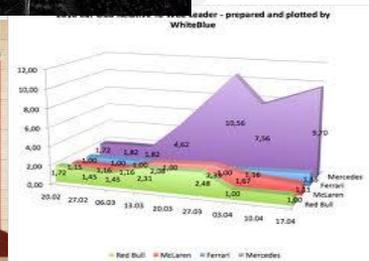
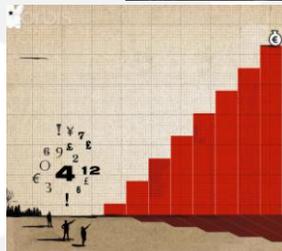
Information

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- Where can I and my family find reliable up to date information about my cancer?
- How can unreliable information be policed and eradicated?
- How can information about warning signs and symptoms be made publicly available?
- Is registration data reliable and is it detailed enough to differentiate for rare sub sets?
- How can I get access to all the information kept about me?

Improvements?

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Improving Treatments

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- What data is being collected about side effects to improve protocols?
- What recording of prescribing patterns is there to assess any variable outcomes?
- What recording of recovery rates and levels is there after surgery?
- What is the level of each hospital and university research spend into rare and less common cancers?

What's ahead?

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Survival

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- What information can I have about survival?
- What is the quality of survival for different treatment options?
- What information is there about long term survivors?
- What other problems may I have in the future as a result of the treatment?
- What tests, investigations should I have to reduce risks?

What Healthcare?

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The Future



- Access to independent, reliable, easy to understand and up to date information.
- Performance comparisons about commissioners, GP's hospitals, specialists and teams
- A culture that expects me to have and supports me to understand all the information I need to make the choices that are in my and my family's best interests
- A system where rare and less common cancers are given equal priority in all aspect of health research, treatment and support