



Less Common Cancer Session

Introductory Presentation for NCIN Conference
Friday 14th June 2013

Simon Davies, Chair, Cancer52

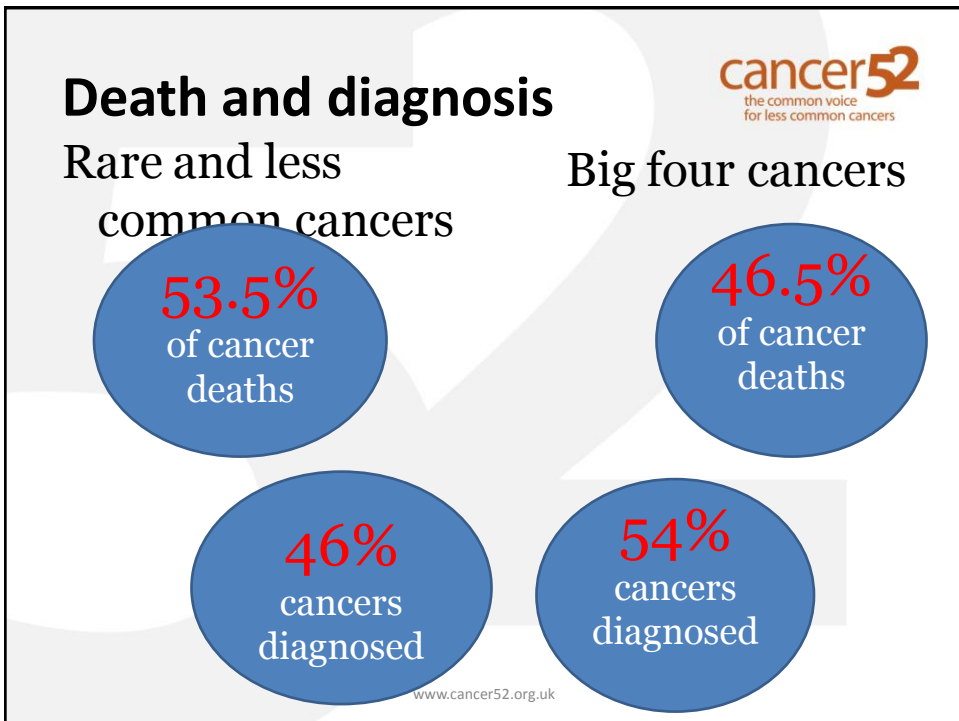
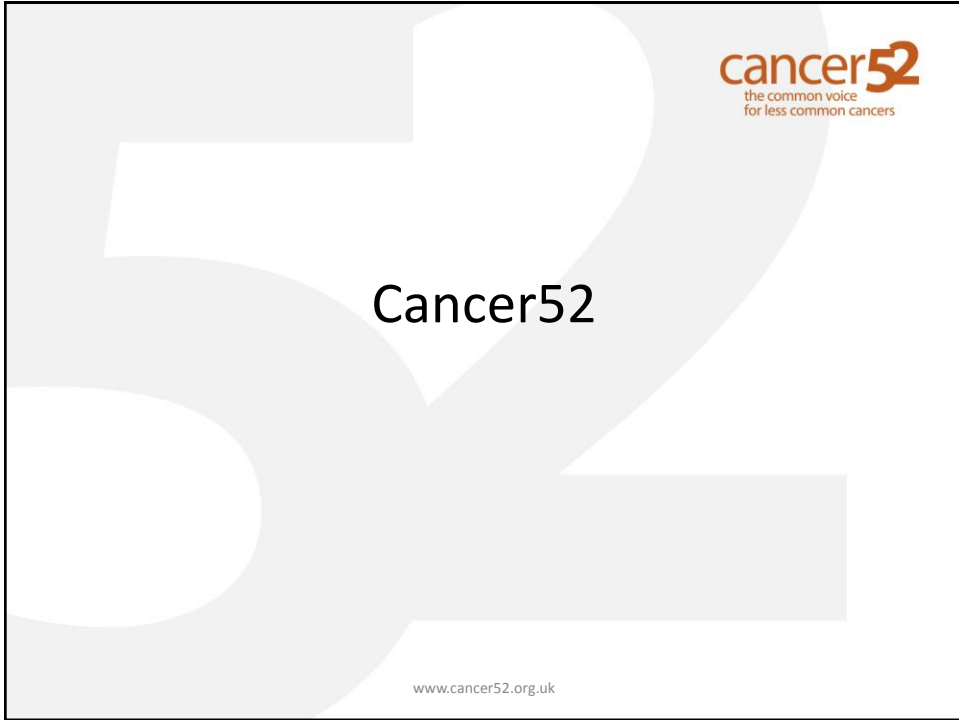
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Structure of session

- Cancer52
- Our speakers and topics
- Questions and closing remarks

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Route to diagnosis



- More rare and less common cancers are diagnosed at Accident and Emergency departments.
- The average percentage for all cancers is 24%, and of the rare and less common cancers only melanoma, uterine, bladder and oesophageal cancers fall below that average.
- For all cancer types, patients are much less likely to survive the next year if they are diagnosed through emergencies.

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Research spend



- In 2006 the combined spend on the five most common cancers (lung, breast, leukaemia, colon and rectal and prostate) made up 60% of the site specific portfolio, about the same proportion as 2002
- Some of the cancers with the lowest five year survival rates (pancreas, oesophageal, lung, all <10% five year survival) have the lowest relative research spend by NCRI partners.
- Conversely, leukaemia and breast cancer have higher survival rates, to some extent reflecting past research successes
- Research spend by cancer death varies enormously by cancer type. £553 is spent on research for every cancer death from pancreatic cancer compared with £3,613 for each death from breast cancer

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Cancer52



- Cancer52 represents numerous organisations* united in improving the future for everyone affected by rare and less common cancers, which account for 53.5% of all cancer deaths in the UK
- We listen, share and represent

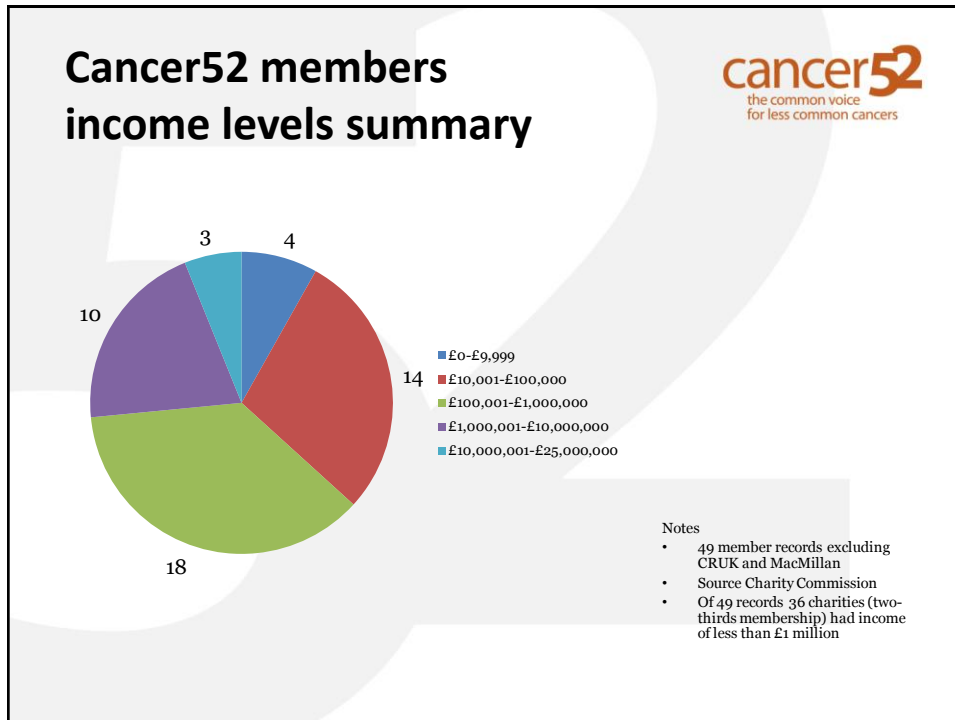
* Currently 63

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Membership



1. The African Caribbean Leukaemia Trust (ACLT) www.aclt.org
2. Adam's Hats (now part of CCLG) www.adamshats.org
3. AMEND www.amend.org.uk
4. AMMF - The Cholangiocarcinoma Charity www.ammf.org.uk
5. Barrett's Oesophagus Foundation www.barrettsfoundation.org.uk
6. Bone Cancer Awareness Trust www.bonecancerawarenesstrust.org
7. Bone Cancer Research Trust (BCRT) www.bcrtr.org.uk
8. Braintrust www.braintrust.org.uk
9. Brain Tumour Research www.braintumourresearch.org
10. Brain Tumour UK www.braintumouruk.org.uk
11. British Lymphology Society www.thebls.com
12. British Thyroid Foundation www.btf-thyroid.org
13. Butterfly Thyroid Cancer Trust www.butterfly.org.uk
14. Cancer Laryngectomee Trust www.cancerlt.org
15. Cancer of Unknown Primary (CUP) Foundation - Jo's friends www.cupfoundjo.org
16. The Children's Cancer and Leukaemia Group (CCLG) www.cclg.org.uk
17. Childhood Eye Cancer Trust www.cheect.org.uk
18. CHILDREN with CANCER UK www.childrenwithcancer.org.uk
19. CLIC Sargent www.clicsargent.org.uk
20. Chronic Myeloid Leukaemia Support Group www.cmlsupport.org.uk
21. CORE www.corecharity.org.uk
22. Debbie Fund www.debbiefund.org
23. GIST Support UK www.gistsupportuk.com
24. Guy Francis Bone Cancer Research Fund www.gfbonecancer.org.uk
25. Heartburn Cancer Awareness & Support (HCAS) <http://www.h-cas.org>
26. International Brain Tumour Alliance <http://www.theibta.org>
27. It's in the Bag - Supporting Men with Testicular Cancer <http://www.uhbristol.nhs.uk/itsinthebag>
28. Jo's Cervical Cancer Trust www.jostrust.org.uk
29. Kidney Cancer Support Network www.kidneycancersupportnetwork.co.uk
30. Leukaemia CARE www.leukaemiacare.org.uk
31. Lymphoedema Support Network www.lymphoedema.org
32. Lymphoma Association www.lymphomas.org.uk
33. Maggie's Cancer Caring Centres (Maggie's Centres) www.maggiescentres.org
34. Melanoma Focus www.melanomafocus.com
35. Meningioma UK www.meningioma.uk
36. MDSUK Patient Support Group www.mdspatientsupport.org.uk
37. Mouth Cancer Foundation www.mouthcancerfoundation.org
38. Myeloma UK www.myelomaonline.org.uk
39. My Name is Not Cancer www.mynamensisnotcancer.com
40. Myrovlytis Trust www.myrovlytistrust.org
41. NET Patient Foundation www.netpatientfoundation.com
42. Neuroblastoma Society www.nsof.co.uk
43. Oesophageal Patients Association www.opa.org.uk
44. Orchid Cancer Appeal www.orchid-cancer.org.uk
45. Ovacom www.ovacom.org.uk
46. Ovarian Cancer Action www.ovarian.org.uk
47. Oxfordshire Oesophageal and Stomach Organisation (OOSO) www.ooso.org.uk
48. Pancreatic Cancer UK www.pancreaticcancer.org.uk
49. Pancreatic Cancer Action www.pancreaticcanceraction.org
50. Pelvic Radiation Disease Association www.prd.a.org.uk
51. Pseudomyxoma Survivor www.pseudomyxomasurvivor.co.uk
52. Rare Disease UK www.caredisease.org.uk
53. Rarer Cancers Foundation www.rarerancers.org.uk
54. Samantha Dickson Brain Tumour Trust www.braintumourtrust.co.uk
55. Sarcoma UK www.sarcoma.org.uk
56. Tanya's Courage Trust www.tanyascourage.org.uk
57. Target Ovarian Cancer www.targetovarian.org.uk
58. Teenage Cancer Trust www.teenagecancertrust.org
59. The Eve Appeal www.eveappeal.org.uk
60. The Ipswich Head & Neck Cancer Support Group www.theipswichheadandneckscg.org.uk
61. Thyroid Cancer Support Group Wales www.thyroidsupportwales.co.uk
62. Wellbeing of Women www.wellbeingofwomen.org.uk
63. Wessex Urology Support Group www.wusg.co.uk



Why us?

- We are
 - a multi stakeholder coalition organisation that engages continually with its members to ensure our policies are member driven
- We have
 - the ongoing authority to speak on behalf of our members
 - unparalleled expertise from individuals within our membership
 - presence and influence beyond the UK, particularly in Europe

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Our vision



- Become the 'go to' organisation of choice for rare and less common cancers for all stakeholders

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Our Aims



- To see a reduction in deaths and improvement in quality of life for people with rare and less common cancers
 - Ensuring an equitable share of attention, investment and voice
 - Improving equity of treatment and supportive services
 - Stimulating and encouraging research
 - Engaging with members and all relevant stakeholders to share expertise and improve outcomes

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Join us!



- Your membership gives you
 - Annual debrief on the work of Cancer52
 - Quarterly all member meetings with relevant speakers and networking opportunities.
 - Minimum of monthly email updates with news and updates relevant to charities working in the rare and less common cancer field
 - Access to members' area of website
 - Representation of rare and less common cancers in key policy making arena
- Membership is free but we will ask you for a voluntary donation

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Speakers and topics

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Speakers & topics



- Nicola Dennis, Public Health England Knowledge and Intelligence Team (West Midlands)
09:45 – 10:00 Gynaecological sarcomas: incidence and survival (England 1985 – 2009)
- Marta Emmett, Public Health England Knowledge and Intelligence Team (East Midlands)
10:00 – 10:15 The morphology of cervical cancer in England: patterns in incidence, treatment and survival
- Dr Katrina Brown, Cancer Research UK
10:15 – 10:30 Presenting brain tumour statistics to the public: unravelling complexity
- Matthew Francis, Public Health England Knowledge and Intelligence Team (West Midlands)
10:30 – 10:45 Endoprosthesis replacements: 30-day readmissions and subsequent amputations (2000-2009)

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Questions to the speakers and Chair's closing remarks



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