



**Delivering transformation in cancer outcomes:**

**Learning Event Cancer Alliance/  
Charity Introduction and Networking Session**

**7th November 2017**



## How can Cancer52 work with Alliances?

<b>Charity:</b> Cancer52	
<b>Contact:</b> Jane Lyons, jane.lyons@cancer52.org.uk	
<b>The main focus/ description of the charity:</b>	
<p><a href="#">Cancer52</a> represents nearly 100 charities and patient organisations working in the field of rare and less common cancers (those outside the 'big four'), covering all aspects of cancer information, support, care and research.</p> <p>We work to ensure that the voice of people with rare and less common cancers is heard at a national level amongst policy makers and influencers and that strategies are implemented. Accordingly Alliances are a critical audience for us.</p> <p>Our key asset and offer to Alliances is to signpost, introduce or help facilitate new partnerships or information exchange between you and a particular charity with specific expertise.</p> <p>We can't include all offers of all our charities within the structure below, so we've highlighted a few examples. But we do ask that you get in touch with us with specific queries and we will take it from there.</p>	
<b>What support can the charity provide for the implementation of the Cancer Strategy to cancer Alliances in the following areas</b>	
<b>Priority area</b>	<b>General Support offer*</b>
<b>Early Access</b> (i.e. Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)	Cervical cancer is the only rare or less common cancer that has a screening programme in place. One of our members, Jo's Trust, works in this field and does a lot of work to drive up attendance at screening
<b>Whole pathway redesign</b> (i.e. Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)	There is work being undertaken on some rare and less common cancers in response to Recommendation 40 of the Cancer Strategy (ref whether MDTs are always the answer for rare and less common cancers).
<b>Rapid diagnostic and assessment models</b> (i.e. Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)	A good number of rare and less common cancers with 'vague symptoms' are particularly reliant on any success of the pilots of multi-disciplinary diagnostic centres (MDDCs) at six sites and we would be happy to work with those cancers particularly affected to help promote and evaluate these MDDCs.
<b>Secondary care networking</b> (i.e. Radiology, pathology, endoscopy networks)	
<b>LWBC- Stratified follow up pathway</b>	Many of the charities and organisations involved with Cancer52 deliver LWBC/survivorship programmes (often tailored to specific types of cancer or "clusters"/patient categories that may not be catered for in mainstream programmes). For example, among Cancer52's



	memberships are major charities that work in women’s cancers, men’s cancers, blood/lymphatic cancers, GI cancers, brain cancers, and so on. Most of these would be interested in and able to work with Cancer Alliances to roll out their programmes to wider patient populations.
<b>LWBC- Recovery packs</b>	As with the LWBC survivorship programmes above, the same applies with recovery packs.
<b>Patient and Community Engagement</b>	Through its diverse membership covering nearly half of all cancer diagnoses, Cancer52 is able to convene or access patient and community engagement either via national or regional events, or via digital/virtual means.
<b>Workforce</b>	A number of Cancer52’s members do or have funded key cancer care posts in specific cancer areas. Cancer52 is able to act as a liaison point between Cancer Alliances and the rare and less common cancer sector regarding workforce issues, and the addressing of workforce gaps.
<b>Local intelligence</b>	With the range and breadth of Cancer52’s membership, there is a ready-made network for local intelligence and national/regional insight. Cancer52 can help facilitate such discussions and networking across the sector.
<b>Other</b>	To reiterate - our door is wide open to assist Alliances. Please email <a href="mailto:jane.lyons@cancer52.org.uk">jane.lyons@cancer52.org.uk</a> or visit the Alliance page on our website

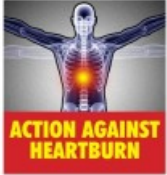
\*Support offer may include producing evidence and best practice recommendation, helping with producing evidence , providing Health and Wellbeing Events, support with workforce, running focus groups etc.

## How can our members work with Alliances?

We asked our member charities what they could offer to Alliances, and responses follow from the following charities

- **Action Against Heartburn**
- **Brainstrust**
- **The Eve Appeal**
- **Kidney Cancer Support Network**
- **Ovarian Cancer Action**
- **Shine Cancer Support**

## Action Against Heartburn



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### Q1 Priority area

*General Support offer:* Early diagnosis and prevention of oesophageal adenocarcinoma

*Region/ Alliance specific support offer:* Action Against Heartburn is a group of 18 organisations with a common interest in oesophageal cancer

### Q2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)

*General Support offer:* justifying GP involvement and endoscopy to determine underlying causes

### Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)

*General Support offer:* Patient group involvement in monitoring of Barrett's Oesophagus patients

### Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)

*General Support offer:* radio frequency ablation for dysplastic condition for adenocarcinoma

### Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)

*General Support offer:* Radio Frequency Ablation. UK Barrett's Oesophagus Registry

### Q6 LWBC - Stratified follow up pathway

*General Support offer:* Post surgical follow up for oesophagectomy / gastrectomy through Oesophageal Patients Association

### Q7 LWBC - Recovery packs

*Respondent skipped this question*

### Q8 Patient and community engagement, workforce and local intelligence

*General Support offer:* OPA (Oesophageal Patients Association) and equivalent organisations

### Q9 Other Respondent skipped this question



## Brainstrust

Helen Bulbeck, Director of services and policy  
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### Q1 Priority area

*General Support offer:* Evidence based support and best practice recommendations for clinical teams and patient and caregivers who are diagnosed and living with a brain tumour

*Region/ Alliance specific support offer:* UK wide

### Q2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)

*General Support offer:* Evidence based reviews and developing knowledge and understanding around early diagnosis for brain tumours. Collaboration with NCRAS and Macmillan on routes to diagnosis. Guidelines for referral.

*Region/ Alliance specific support offer:* UK wide

### Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)

*General Support offer:* Thorough knowledge and collaboration with NICE of the revised guidance for brain and CNS cancer. brainstrust is on the committee and is working on new resources for people who are affected by a brain tumour. This work includes decision aids.

*Region/ Alliance specific support offer:* UK wide

### Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)

*General Support offer:* Engagement with evidence based review of diagnostic and assessment models for brain tumour diagnosis, for GPs and for patients and caregivers.

*Region/ Alliance specific support offer:* UK wide

### Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)

*General Support offer:* Central hub for networking, ensuring that patients and caregivers can be co pilots in their care.

*Region/ Alliance specific support offer:* UK wide

### Q6 LWBC - Stratified follow up pathway

*General Support offer:* Dissemination of information around the follow up and living with brain cancer - signposting, support, setting out expectations

*Region/ Alliance specific support offer:* UK wide

### Q7 LWBC - Recovery packs

*General Support offer:* Specific coaching to ensure that people are being supported in the right way and that they can access the services they need. Information and guidance to achieve maximum quality of life in this phase.

*Region/ Alliance specific support offer:* UK wide

### Q8 Patient and community engagement, workforce and local intelligence

*General Support offer:* Coaching, signposting, support, development of communities to ensure that everyone can achieve and work together so that they feel resourced and resilient.

*Region/ Alliance specific support offer:* UK wide

### Q9 Other

*General Support offer:* We help thousands of people who have a brain tumour to feel more in control, feel less alone and be less afraid in the face of a terrifying diagnosis. We work with hospitals to secure care pathways, and because we truly understand, we're able to campaign for the brain tumour community to help solve real issues.



**the eve** The Eve Appeal  
**appeal**

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#### **Q1 Priority area**

*General Support offer:* raising awareness of health screening and signs and symptoms of gynae cancer

*Region/ Alliance specific support offer:* country wide reach

#### **Q2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)**

*General Support offer:* increased uptake in cervical screening programme. development of GP and primary care nurse education / support packages.

*Region/ Alliance specific support offer:* developing a working partnership with public health Wiltshire as a pilot supporting primary care education

#### **Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)**

*General Support offer:* work with British Gynaecology Cancer Society on pathway guideline writing

*Region/ Alliance specific support offer:* country wide reach

#### **Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)**

*General Support offer:* working with BGCS ( as above ) , commissioning sub group representation

*Region/ Alliance specific support offer:* country wide reach

#### **Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)**

*General Support offer:* taking part in NICE specialist committee for diagnostic tools

*Region/ Alliance specific support offer:* country wide reach

#### **Q6 LWBC - Stratified follow up pathway**

*General Support offer:* input from specialist information nurse for The Eve Appeal also supporting MacMillan COT MDT.

*Region/ Alliance specific support offer:* country wide reach

#### **Q7 LWBC - Recovery packs**

*General Support offer:* happy to contribute to information packs

*Region/ Alliance specific support offer:* country wide reach

#### **Q8 Patient and community engagement, workforce and local intelligence**

*General Support offer:* reach out to charity supporters and stakeholders

*Region/ Alliance specific support offer:* country wide reach

#### **Q9 Other** *General Support offer:* keen to be involved in information gathering events and disseminate good practice/



## Kidney Cancer Support Network

Sharon Deveson Kell, Head of Medical Relations  
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### Q1 Priority area

*General Support offer:* KCSN can provide real world evidence for the kidney cancer treatment pathway from the KCSN patient registry. We can also provide feedback from our network of 1000+ kidney cancer patients and families to inform person-centred care for cancer patients in the NHS.

### 2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)

*General Support offer:* KCSN can raise awareness of signs and symptoms of kidney cancer (e.g. blood in urine) for earlier diagnosis through social media campaigns, e.g. Go Green for Kidney Cancer. We also provide patient-friendly information about kidney cancer on our website, including information about access to treatment schemes, such as EAMS, CDF, IFRs etc. Our Clinical Trials Hub helps to improve awareness of clinical trials in the UK. The hub includes our kidney cancer clinical trials database for patients/families to search for suitable trials in their locality. The KCSN Patient Champion Programme aims to educate patients/families about UK kidney cancer clinical trials to improve recruitment and retention of patients on trials - for early access to new, innovative medicines.

### Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)

*General Support offer:* KCSN can assist with raising awareness of less invasive ablation techniques for small renal masses, and SABR for the treatment of kidney cancer metastases. We can provide patient input for whole pathway redesign from our network of 1000+ kidney cancer patients and families, to ensure pathways are person-centred.

### Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)

*General Support offer:* Signs and symptoms of kidney cancer can be vague and confused with UTIs. KCSN can help raise awareness of signs and symptoms of kidney cancer among the general public, and the work of the rapid diagnostic and assessment centres to improve early diagnosis of kidney cancer in people with vague symptoms.

### Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)

*Respondent skipped this question*

### Q6 LWBC - Stratified follow up pathway

*General Support offer:* KCSN is the largest and most active network of kidney cancer patients and families in the UK. We can provide real world evidence regarding follow-up after treatment from our patient registry. We can also provide patient input to new, holistic, person-centred after-care pathways. The KCSN kidney cancer helpline is operated by cancer patients and provides support to patients and families, including long-term survivors - KCSN can assist with supported self-management of patients during stratified follow-up pathways.

### Q7 LWBC - Recovery packs

*General Support offer:* KCSN can provide patient input to kidney cancer recovery packs, including health and wellbeing events, and rehabilitation of patients living with and beyond cancer.

**Q8 Patient and community engagement, workforce and local intelligence** *General Support offer:* KCSN can provide patient and public input from our network of 1000+ kidney cancer patients and their families to ensure person-centred care for cancer patients.





## Ovarian Cancer Action



Marie-Claire Platt, Head of Operations and Campaigns  
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### **Q1 Priority area**

*General Support offer:* BRCA testing (recommendation 36)

### **Q2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)**

*Respondent skipped this question*

### **Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)**

*General Support offer:* BRCA testing in ovarian cancer treatment pathway

### **Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)**

*Respondent skipped this question*

### **Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)**

*Respondent skipped this question*

### **Q6 LWBC - Stratified follow up pathway**

*Respondent skipped this question*

### **Q7 LWBC - Recovery packs**

*Respondent skipped this question*

### **Q8 Patient and community engagement, workforce and local intelligence**

*General Support offer:* Workforce training on BRCA testing & some regional data on whether testing is being offered

### **Q9 Other**

*Respondent skipped this question*





## Shine Cancer Support

**Ceinwen Giles, Director of Partnerships and Evaluation**  
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**07837887247**



### **Q1 Priority area**

*General Support offer:* We provide tailored support and information to any adult diagnosed with any type of cancer when they are in their 20s, 30s or 40s. We provide expert information and recommendations on young adults with cancer and assist with producing evidence. We have specific expertise in peer support for young adult cancer patients, as well as engagement with young adults with cancer both in person and online via social media.

*Region/ Alliance specific support offer:* Whole of UK

### **Q2 Early Access (ie Lung case finding, Increased uptake of bowel screening, Innovative approaches for supporting patient navigation and GP knowledge and education)**

*Respondent skipped this question*

### **Q3 Whole pathway redesign (ie Optimal lung pathway, FIT for symptomatic patients, Colorectal pathway, including straight to test, MRI in the prostate pathway)**

*Respondent skipped this question*

### **Q4 Rapid diagnostic and assessment models (ie Diagnostic hubs (ACE Wave 2 model), Rapid access to diagnostics, Vague symptom pathways)**

*Respondent skipped this question*

### **Q5 Secondary care networking (ie Radiology, pathology, endoscopy networks)**

*Respondent skipped this question*

### **Q6 LWBC - Stratified follow up pathway**

*Respondent skipped this question*

### **Q7 LWBC - Recovery packs**

*General Support offer:* We provide working after cancer workshops and also support and information to support people in their return to work.

### **Q8 Patient and community engagement, workforce and local intelligence**

*Respondent skipped this question*

### **Q9 Other**

*General Support offer:* Providing health and well-being events for young adults with cancer (25 to 49 years), and supporting the HWB events of other healthcare organisations.

*Region/Alliance specific support offer:* Whole of UK



[http://www.cancer52.org.uk/supporting-cancer-alliances-2/  
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