

**Written submission for the APPG on Less Survivable Cancers**

OOSO is a small patient and carer focussed support charity, based in Oxfordshire, but serving people and communities mostly in Southern England, but also nationwide, and occasionally internationally. We are all volunteers. Our membership is a mixture of former and current oesophageal and stomach cancer patients, bereaved families, clinicians and researchers.

The following comments are based on the experiences of our members, collated at an open forum of 70 guests earlier this year.

**Themes: earlier detection of the less survivable cancers and innovating faster diagnosis.**

**1) Public awareness**

• The general public has little to no knowledge or awareness of oesophageal and stomach cancer, and most other cancer types;

• Greater awareness will improve people’s understanding of what they can do to lessen their risk of developing these cancers, and by understanding the symptoms seek an earlier diagnosis;

• Social media should be used to raise awareness;

• Schools should adopt ‘health and wellbeing’ sessions that include awareness to cancers and risk factors;

• Public awareness can be improved through labelling food products, especially highly processed foods, sugar-based products and alcohol, simply making clear these are known risk factors (all be they not proven ‘causes’ of cancer). Similarly to health warnings on cigarette packets, a cultural shift would take place.

**2) Primary care**

• challenges getting a timely appointment with a GP;

• difficulties getting a face-to-face appointment, rather than a phone call;

• GPs not familiar with the symptoms of less survivable cancers;

• GPs having little experience meeting patients with these cancers;

• GPs having heavy workloads and not enough quality time with patients;

• GPs being the traditional route for referral is outdated and not the only option; • GPs risk-based diagnostic priorities are inadequate, cancer should be the first possibility, not the last;

• GPs tend to downplay the possibility of cancer in younger people, which is a big mistake; • GPs should be offered online awareness training sessions as part of their continual assessment/accreditation;

• Screening programs should be offered to people over a certain age, we would suggest 40; • Diagnostic capacity should be increased through Community Diagnostic Centres, Pharmacies and mobile units, reaching poorer inner-city communities and remote/rurally based people • People should be able to self-refer to CDCs, Pharmacies and mobile units – either simply turn up, or make a prior appointment by phone or online;

• CDCs should have endoscopy units;

• GPs, CDCs, Pharmacies to be better connected with local patient support groups, signposting patients to each other, for better quality information, helping to reduce diagnosis timescales.

**3) Secondary care**

• Secondary care needs to be properly resourced;

• Cancer patient targets **must be met** and rapidly addressed if not achieved; • Receiving and scheduling referrals could be speeded up, e.g. patients to be called on the day of referral to attend an appointment within a few days – i.e. withing the two week wait list; • The capacity for endoscopy screening should be sufficient to meet the demand; • Endoscopies should be carried out under mild sedation rather than throat spray, despite this taking longer to do there is evidence fewer cancers are missed;

• Biopsy screening should be quicker, within a week, and results shared with patients face to face soon after the examination;

• Discussions should be recorded, given with empathy and written supporting information; • Outpatients appointments should be face to face initially and within a week of the test results being available;

• MDTs should have interim discussion forums, so the weekly meeting isn’t a hurdle to initiating a treatment plan;

• Patients need to be kept informed and in direct contact with a known person (the Cancer Nurse Specialist, CNS role is a vital one);

• Further tests, staging or investigations into complications need to be prioritised with urgency to achieve the 62-day target;

• A&Es must have expertise to hand recognising the acute symptoms of these cancers, to eliminate mis-diagnosis or delays;

• All elements of the patient pathway need to run smoothly and in parallel to shorten timescales – e.g. prompt referrals to specialist dietitians who keep patients well enough for treatments to go ahead;

• Referrals to tertiary care specialists needs to be acted upon quickly.

**4) Research and Trials**

• There should be greater investment in applied research and trials for less survivable cancers; • Research and trials for these cancers should be prioritised over other less critical illnesses, with bureaucracy and barriers to successful bids lowered;

• Research into early diagnostics should be a priority, aiming to achieve a cheap simple approach to routinely screen large numbers;

• Trial periods should be shortened, to bring new treatments into use sooner; • Research and trials undertaken in other countries where standards of rigour are comparable should be adopted and not repeated, saving valuable time and money;

• Successful drugs, therapies and surgical techniques routinely used in other countries should be adopted more readily;

• Centres of excellence for each less survivable cancer should be established, pooling resources and expertise, reducing duplications of effort and speeding up outcomes.

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