

National Assembly for Wales

[Health and Social Care Committee](#)

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from Pancreatic Cancer UK- CDP 39

Committee Clerk,
Health and Social Care Committee,
National Assembly for Wales,
Cardiff Bay, CF99 1NA

23rd April 2014

Dear Sir/Madam,

Re: Cancer Delivery Plan Inquiry

1. Pancreatic Cancer UK welcomes the opportunity to respond to the Health and Social Care Committee's Inquiry into progress made in implementing the Welsh Government's Cancer Delivery Plan.

About Pancreatic Cancer UK

2. Pancreatic Cancer UK is the only national charity fighting pancreatic cancer on all fronts: patient and carer support; information; campaigning; and research. We provide a UK-wide, expert and personalised support and information service, staffed by pancreatic cancer specialist nurses. This provides easy access to the best and most up-to-date information on pancreatic cancer to patients, their carers and families. We also run online discussion forums for pancreatic cancer patients, their families and carers to enable them to share experiences, information, inspiration and hope.
 - 2.1 We fund innovative research that makes the most impact with limited resources and leverages additional investment - and development of new talent - through our own research expenditure.
 - 2.2 Working closely with patients and their families and carers, clinicians and other healthcare professionals, researchers, politicians and policy makers we seek to increase awareness of the disease and campaign to bring about improved outcomes in care and treatment.

Incidence, Mortality and Diagnosis

Support

Information

Research

Campaigning

Registered charity No: 1112708/ A company limited by guarantee/ Registered in England No5658041

3. As the WCISU's April 2014 summary report showed, pancreatic cancer has the lowest one-year and five-year survival rates of the 21 most common cancers, the latter figure standing at under 4%. Pancreatic cancer is currently the sixth most common form of cancer in Wales, with 487 new cases diagnosed and 440 deaths recorded in 2012.
- 3.1 As with the rest of the UK, diagnosis of pancreatic cancer is very often made at an advanced stage. Because of this across the UK only between 10% and 20% of patients with pancreatic cancer are eligible for curative surgery.
- 3.2 This is largely because of late diagnosis: over half of pancreatic cancer patients across the UK are diagnosed via emergency admission with more than 40% of patients visiting their GP three or more times before they are even referred to hospital. Often GPs mistake the symptoms for some other condition and begin treatment for an unrelated condition.
- 3.3 Section 6.2 of the Cancer Delivery Plan describes the need for Local Health Boards to raise awareness among the public and GP awareness of cancer symptoms generally. Given the late diagnoses of many pancreatic cancer patients specific campaigns may be needed to help tackle the extremely and persistently low survival rates for pancreatic cancer.
- 3.4 We are particularly keen to see GPs provided with Risk Assessment Tools to help them identify cases correctly and early. We would also like to see GPs given faster access to investigations, including CT scans, something which we are only aware of happening routinely in a limited number of places, for example, through a rapid access clinic in Southampton.

Access to treatment

4. Section 6.3 of the Cancer Delivery Plan talks of ensuring patients have fast and effective treatment and care, whilst section 6.4 refers specifically to caring for those with metastatic cancer. As NICE guidance applies to Wales, but Wales does not have a Cancer Drugs Fund, patients in Wales are potentially missing out on new treatments until NICE makes a decision. This is the case currently with Abraxane, which is approved for inclusion on the CDF list of drugs in March 2014, but is not due for a decision from NICE until January 2015.
- 4.1 The only alternative to waiting for NICE approval is through Individual Patient Funding Requests. However, this seems, from anecdotal evidence, not to provide patients with access to the treatments they need and is a long and complicated process. Put simply, with only a 2-6 month median survival rate from diagnosis, time is something that those with advanced pancreatic cancer do not have.
- 4.2 We would like to like to see this system reviewed to remove the current inequality of treatment between patients in Wales and England.

Patient Care

5 Section 6.4 of the Plan sets out a goals for improving patient care, including better communication. We support the introduction of the Wales Cancer Patient Experience Survey as this will help to track progress in delivering improved care and patient information and communication in future. We hope this survey will become an annual fixture.

5.1 The topline Survey results show variations in the patient experience for different cancer types. This mirrors findings in the NHS England Cancer Patient Survey, where pancreatic cancer patients report less satisfaction with information they are given, longer amount of time and more visits to their GP before diagnosis etc. These variations need to be assessed and where significant differences in performance are identified, actions plans should be drawn up to remedy the situation.

5.2 Section 6.4 also talks of the need for Multi-Disciplinary Team models of treatment. We fully support this approach and especially want to see that all Pancreatic MDTs include a dietician. From the many contacts our Support Line receives, it is clear that not all patients are receiving the vital dietary advice and treatments they need to manage their condition most effectively. This is true across the whole of the UK.

Miscellaneous

6 Local Health Boards have an important role to play in improving cancer care across Wales. We welcome the fact that each LHB has to produce its own cancer delivery plan but are concerned that there is a lack of consistency in approach. We would also welcome specific sections within those plans aimed at tackling different cancer types, or targeting action on more recalcitrant cancers – i.e. those types of cancer which have seen five-year survival rates remain below 20% for a long period of time – to help bring about some much needed improvement..

Thank you for the opportunity to submit evidence to the national assembly for Wales' Health and Social care Committee Inquiry.

Yours sincerely

Support

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