

Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales, June 2020

Tenovus Cancer Care is Wales' leading cancer charity. Our aims are simple. We want to help prevent, treat and find a cure for cancer.

We do this by offering support, advice and treatment to cancer patients and their loved ones. We also promote healthy lifestyles and fund cancer research to find new ways to prevent it, diagnose it, and treat it.

We welcome the opportunity to respond to this important consultation.

Organisational impact

Organisationally, the COVID-19 crisis has impacted both our organisational ability to operate as well as raised significant challenges for the cancer services that are so vital to people affected by cancer.

1. Fundraising

- a. The pandemic and associated lockdown has severely impacted our income generation, principally as a consequence of the closure of our retail estate, the cancellation or postponement of many fundraising events and the inability of our Friends of Tenovus Cancer Care groups, including Sing with Us choirs, to meet.
- b. While governmental schemes, such as the UK Government's Coronavirus Job Retention Scheme and the Welsh Government's Business Rate Relief scheme, have allowed us to mitigate some of the costs of operation, many others including the fixed rental costs on our retail estate, have persisted.

2. Charitable activities impacted

- a. The crisis has also impacted our ability to deliver services that support people affected by cancer. With us having to change and adapt our service delivery, against the backdrop of a challenging financial situation, and with the need to protect our ability to deliver vital services in the future, we took the decision to 'furlough' the majority of our staff. This included many of our choir team, and our research and policy functions.
- b. The impact of lockdown has resulted in the emotional and physical benefits enjoyed by participants in our Sing with Us choirs has not been fully realised. An average 16 physical events per week attended by around 1,350 people affected by cancer were replaced by 9 virtual choir events delivered by a reduced Sing with Us choir team. We anticipate this new online model to continue for some time given the vulnerable nature of our choristers, and the high-risk nature of singing in an enclosed space.
- c. Our Research provision has also been modified as a consequence of COVID-19. A number of our funded researchers have been seconded to COVID-19-related research or to the front line. The lockdown has also meant that laboratories have been closed and focus groups have been

unable to meet. Due to the volatile financial climate, we have delayed the commencement of certain projects that had otherwise been agreed and have sadly had to cancel another. We are currently reviewing how to proceed with future grant calls.

- d. Our Mobile Support Units (MSUs) deliver chemotherapy and lymphoedema treatments to people in their own communities, closer to home. We have four units in total. Two (MSU 2 and MSU 3) are based in Wales and, due to a lack of take-up from Health Boards in Wales, two others (MSU 1 and MSU 4) were redirected to serve patients in England.
 - i. MSU 1 and MSU 4 have continued to operate in England throughout the pandemic, with a slight reduction in capacity due to social distancing rules.
 - ii. MSU 2 provides lymphoedema treatments on behalf of the Welsh NHS and as a result of that service being suspended centrally our MSU 2 was off the road.
 - iii. MSU 3 is normally commissioned to provide chemotherapy by Swansea Bay UHB and Velindre. Sadly the Swansea Bay UHB element of our MSU provision ceased during the acute phase of the pandemic.
 - iv. Across all our MSU operations the lack of access to PPE was a significant limiting factor on our ability to operate.

Impact upon charitable aims

3. Reduced referrals

The number of people entering the Single Cancer Pathway fell by an average of around 60% in April 2020 compared to the start of the year. Not enough is currently known regarding the multiple dynamics behind this, however it could be explained by a mixture of:

- a. people being reluctant to visit a GP due to concerns about social distancing,
- b. people not wishing to add 'burden' to the NHS during the acute phase of COVID-19.
- c. greater gatekeeping by primary care regarding those individuals able to secure a GP appointment

We understand that the public will have been anxious regarding points (a) and (b) above, and feel that public messaging was not sufficiently clear, or reassuring, particularly in the initial acute phase, to ensure that an individual's propensity to present with symptoms was not reduced

SCP figures in April indicated an increased percentage of people starting treatment in that month. It is possible that this is due to (i) a data lag of people who had been referred the previous month being diagnosed and starting treatment, but also possibly (ii) as a result of a greater proportion of those entering the pathway doing so with red-flag symptoms, as those with less severe or more vague symptoms stayed away from primary care.

To ensure that (c) is not a long-term phenomenon it is vital that where clinically appropriate and as we enter the recovery phase, we ensure that rapid gains made in terms of shifting a greater percentage of consultations online and via videoconference are not lost.

4. The effects of diagnostic and treatment delays

- a. We know that earlier diagnosis leads to improved survival outcomes for cancer. It is too early to tell what the specific impact may be, however it is worryingly inevitable that there will be a significant impact upon cancer mortality as a result of stage-shift from paused screening, delayed diagnosis and treatment during the acute phase of the COVID-19 crisis.
- b. Capacity, once restored, will face significant difficulties clearing historical backlogs – and that is to say nothing about the pre-COVID-19 difficulties of engaging already harder-to-reach

communities and our ambition to see progressive improvements in detection and diagnostic outcomes. We fear that previous ambitions, particularly around bowel cancer screening optimisation may take a significant amount of time to recover.

5. The communication issues

- a. Much of the initial communication regarding the nation's lockdown was erroneously reported from a UK Government-centric perspective, not taking into account the devolution of public health in Wales. While this has improved as time has gone on, and the public appears more au fait with the realities of devolved competencies, this is certainly not universal and scope for confusion remains.
- b. While we welcome the shift to a digital-first approach to patient engagement, it is absolutely vital that all communication channels are employed for relaying information regarding health, and where specific to the individual, is tailored to the individual concerned. 'Shielding' is a good example where the decision was taken too late in the day to be effectively communicated to those concerned via any method other than via mass broadcast media, inherently risking being confused with advice from other nations of the UK (England, specifically) in the process. During the initial shielding advice we are aware of a number of people who received letters who didn't need them and vice versa.

As we begin to exit the acute phase of the pandemic it is vital that the Welsh NHS embraces a communications strategy that overcomes these barriers, and learns lessons from difficulties it has had, in preparation for possible future waves to ensure that screening and diagnostic services are not permanently incapacitated.

Opportunities for rebuilding

6. Social prescription

We all saw the power of communities coming together this spring during the acute phase of the pandemic, particularly ensuring that shielding groups remained catered for. However, it's undeniable that this period has led to an increase in social isolation and loneliness for many, if not most of us.

As lockdown eases the benefits of social prescription options, such as our Sing with Us choirs, will be more important than ever in helping to overcome loneliness and social isolation in our communities – whatever form that takes.

7. Closing the diagnostic gap

As we exit lockdown and begin to resume screening and diagnostic services there is a danger of a tsunami of pent-up demand being unleashed from people who have avoided going to GPs for less serious or vague cancer symptoms.

We risk the NHS being overwhelmed with referrals, with diagnostic capacity already a bottleneck in cancer. We see Rapid Diagnostic Centres, already a very valuable tool, as a means of helping relieve pressures in the system caused by deferred demand induced by COVID-19. We understand that the Wales Cancer Network is looking at how these may be rolled out across Wales but understand how capacity may be constrained across the NHS estate. We would be willing to help provide flexible capacity through our Mobile Support Units, which could also have played a role during the acute COVID-19 phase in providing testing space. However, it would be fair to say that conversations with Local Health Boards regarding uptake of Mobile Support Units has been frustrating.