

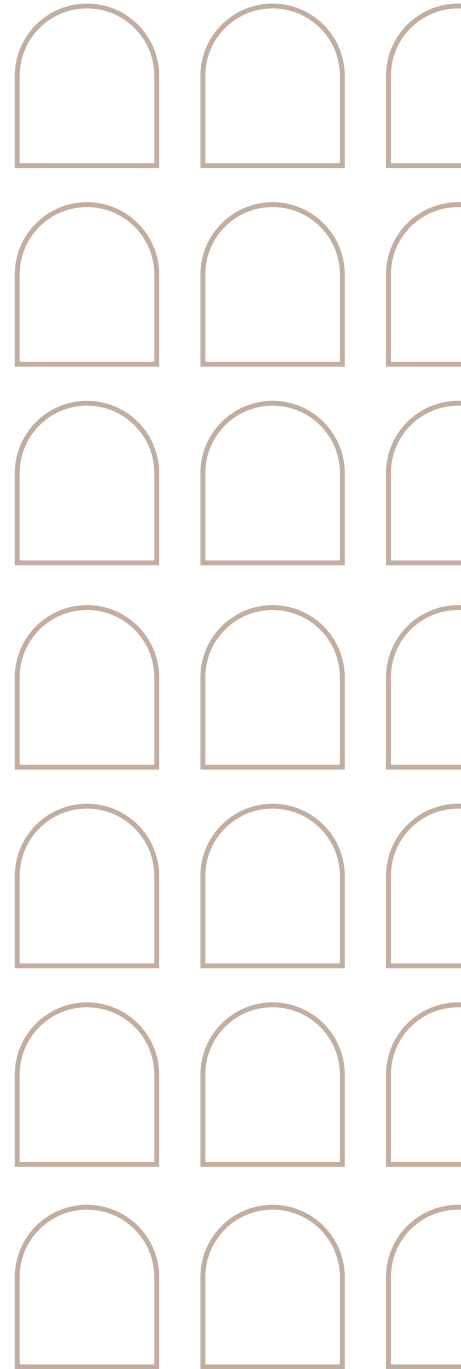
STG Policy Papers

# POLICY BRIEF

**“CANCER WILL NOT WAIT FOR  
COVID-19 TO PASS”: PATIENT  
MOBILISATION IN HEALTH POLICY  
MAKING IN THE FACE OF A PUBLIC  
HEALTH CRISIS**

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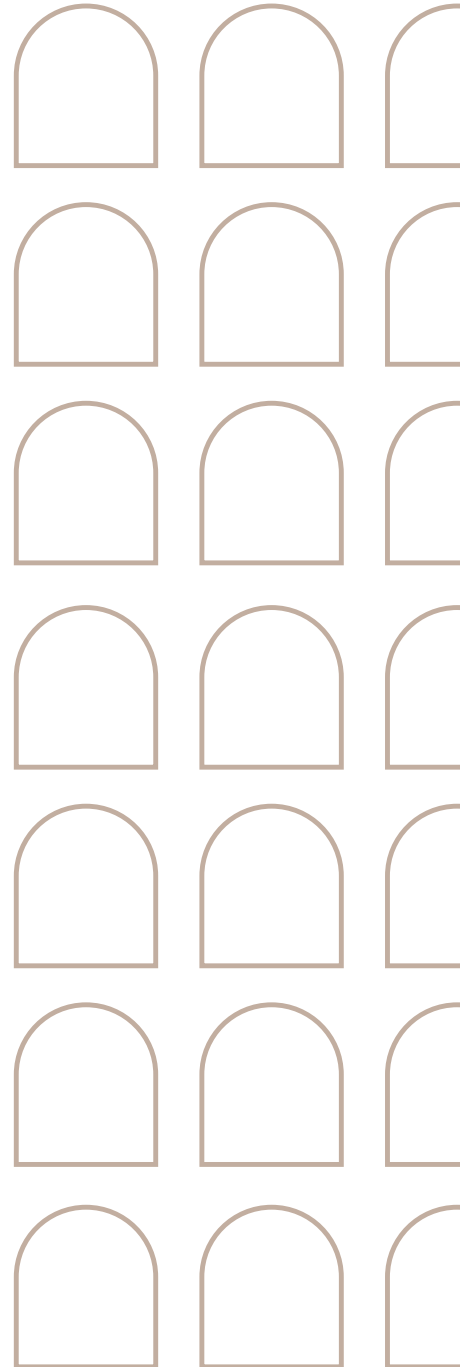


## EXECUTIVE SUMMARY

This paper explores the impact of COVID-19 on patient organisations in the health field by focusing on four cancer patient organisations and examining their specific responses to COVID-19 restrictions and associated lockdown measures in the UK. Also, it examines the wider implications of these employed responses for Patient and Public Involvement (PPI) in health policy making. To mitigate the impact of COVID-19, which triggered a systemic shock and placed significant strain on essential cancer services, cancer patient organisations had to adapt their approach and operations across four key structural domains: donations, staffing, services, and campaigning. At its foundation, this study uses thematic analysis in the broad sense to explore the changing representations of selected patient organisations across the four identified structural domains by examining the content on each of their webpages, which act as 'public facing' interfaces for each organisation. This study showcases the varied responses of patient organisations when faced with a public health crisis and presents policy recommendation to secure the patient's voice in health policy making process.

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## 1. INTRODUCTION

COVID-19 has triggered a systemic shock and placed significant strain on essential cancer services in the UK, with cutbacks of cancer screenings, tests, and treatments having an unprecedented impact on patients (Cancer research UK, 2020; BMJ, 2020). This paper explores the efforts of cancer patient organisations in mitigating the impact of COVID-19 on cancer patients by examining the specific responses of small and large organisations to the restrictions and associated lockdown measures across England and Scotland.

Patient organisations are typically third sector entities representing patients, carers, or both, which provide support and advocate for people with certain conditions. In the UK they provide a key function in ensuring that the patient voice is heard in the policymaking process and service design and delivery (Williamson, 2010). The advocacy role of patient organisations has been strengthened in the past few decades, in England and Scotland, following the new statutory framework for Patient and Public Involvement (PPI) that was introduced in the early 2000s (NHS, 2000; NHS, 2007). The new framework encourages patient voices throughout the different stages of the policymaking and service design/delivery processes and gives them a seat at the table in NHS boards and beyond.

With lockdown measures enforced on several occasions in England and Scotland since late March 2020, the voluntary health sector in general, and patient organisations in particular, have experienced disruption to their daily operations and were required to respond rapidly to the changes in their physical and political environments. This has prompted organisational change. This paper reports on how small and large cancer patient organisations remained active as advocates in the policymaking process during this global health crisis while the concept of PPI is utilised to explore the implications of the impact of COVID-19 on patient mobilisation in health policy making in the face of a public health crisis.

## 2. COMPARATIVE DESIGN

Exploratory in nature, this study design was case-oriented, and the units of analysis were picked from a range of health and social care charities in England and Scotland. The databases of the patient organisations were retrieved from the National Voices in England (National Voices, 2022) and the Voluntary Health Scotland (VHS) in Scotland (Voluntary Health Scotland, 2022). This helped in identifying cancer patient organisations operating in each respective nation.

In addition, to ensure this study could examine the organisational change of cancer patient organisations as they mitigate the impact of COVID-19, the size and focus of the cancer patient organisations were taken into consideration when picking the four case studies; two organisations from England (Bowel Cancer UK - England; Pancreatic Cancer Action) and two from Scotland (Bowel Cancer UK - Scotland; Pancreatic Cancer Scotland). The choice of picking, in each country, one large organisation, which represents a more common cancer type such as one of the big four – breast, bowel, lung, and prostate (Cancer52, 2020) – and one small organisation, which represents the less common/rarer types of cancer, was guided by Nicholas and Broadbent (2015). They suggest that comparing different sizes of organisations will account for the different structures and resources, which in turn will help in achieving a more nuanced understanding of the chosen strategic responses.

In addition, Bowel Cancer UK was chosen as it operates in both England and Scotland and offers a lens into the impact of the different health policy arena organisations generally operate in. Once health policy was fully devolved to the Scottish Parliament, it became the typical example of post-devolution distinctiveness in the UK (Stewart, 2013). Patient and Public Involvement (PPI) is a sub-field of health policy, helping shape the health policy environment and offering a framework in which patient organisations operate as representative of the patients. With PPI being a particularly relevant field of policy in the Scottish context, it offers a finer comparative distinguishing of Scotland's divergence from England in health

policy matters and the systems in which cancer patient organisations operate. Thus, enabling observers to examine the processes through which patients are involved in collective decision making (Bovenkamp and Vollaard, 2018).

The Scottish public involvement agenda in health policy making introduced the concept of 'Patient Focus and Public Involvement', which was seen as a novel commitment to a more collective approach. From 2007, with the introduction of the SNP's Better health, better care White paper (Scottish Government, 2007), the general approach to the role of the public in the management of services diverged from the approach in England, which employed a more privatised interpretation of public involvement at the core of its vision for the NHS in the late 1990s (Stewart, 2013).

Examining the websites of cancer patient organisations and their published policy reports was the foundation of this examination of strategic responses to COVID-19 and how they adapted their operations to the new policy environment. Given that websites are the 'most public of faces' for activist organisations (Bennett and Segerberg, 2013: 60). Where a response to COVID was not stated on the home webpage, a more thorough search of the website had to be conducted to ascertain how the organisation responded to COVID-19. Beyond the websites of the organisations, a selection of reports and policy-related texts were read; those that concerned organisational response to COVID-19 policies were chosen for in-depth analysis.

### **3. ORGANISATIONAL CHANGE**

Exploration of organisational change among cancer patient organisations, due to external drivers/effects, involves measuring organisational characteristics over several different activities. According to McKelvey (1982), the activities should be selected on the basis of their importance to organisational survival and centrality to an organisation's core competencies (Prahalad and Hamel, 1990). In their research, Jones, Baggott and Allsop (2004), focused on the role of patient organisations

in representing and promoting the collective interests of patients, users, and carers in the UK national policy process. They carried out a semi-structured questionnaire survey of 123 patient organisations, alongside semi-structured interviews with key informants from 39 patient organisations and semi-structured interviews with 31 policy actors. Their results showed the diversity in the origins, scope and structure of patient organisations, alongside the breadth of policy and service provision activities undertaken by them. The authors identified three main activities as important and as meeting the criteria of being central to patient organisations' survival: organisational maintenance activities, service activities, and policy-related activities. The impact on these activities is explored below.

#### **3.1 Organisational maintenance activities**

Organisational maintenance activities can be broken-down into donations and staffing. To carry out their activities, cancer patient organisations need to raise the necessary financial resources to do so (Jones, Baggott, and Allsop, 2004). Such financial capital usually comes from donations, fundraising events, campaigns, corporate collaborations, and funding from the government and/or pharmaceutical companies. However, with lockdown measures implemented and social distancing in place, the usual outlets for fundraising, such as events, corporate partnerships and charity runs, were paused. For example, Pancreatic Cancer Action noted on their website that 'as a charity we are facing the prospect that many of the events and activities we depend on to fund our vital work are being cancelled or postponed'. Hence, to mitigate this, organisations were required to respond and adapt quickly to remain operational. The cancer patient organisation 'Bowel Cancer UK - Scotland' began hosting virtual fundraising events such as 'Brew Together', 'Walk Together' and virtual quizzes. 'Pancreatic Cancer Scotland' also opted for virtual fundraising events, such as 'PJs for Pan Can' to raise donations.

Similar to many organisations and charities in the voluntary sector, the staffing structure in

patient organisations is often a combination of employed professionals, policy specialists and volunteers, with large charities hiring professionals and policy specialists for their staff, given their financial ability to do so, whereas smaller organisations often rely on volunteers to operate (Jones, Baggot, and Allsop, 2004). In the context of the four case studies, an examination of the team profiles on the organisations websites has shown that the small organisations based in England and Scotland both seem to rely on volunteers – many of whom have dealt with or are dealing with the related cancer – unlike the larger organisation of Bowel Cancer UK, who, according to their team profiles on the Scottish and English website, seem to hire professionals based on expertise and policy experience. The larger organisations have faced less of a direct impact on their staffing resource from the government’s shielding requirements, compared to smaller organisations. Smaller organisations have been more directly impacted by the shielding requirements and/or the caring duties associated with lockdown measures which in turn has restricted their available time to campaign and support their communities. For example, Pancreatic Cancer Scotland’s staff has been working in ‘a reduced team from home’ throughout the pandemic. With the reduced capacity, they have focused their effort and services on policy and patient advocacy. Furthermore, they have been engaging with the Scottish Government’s Cancer Policy Team on a weekly basis to ensure that the concerns of their community patients, which have been collected during the live Q&A webinars and zoom calls are fed directly into the government’s response to the pandemic and not overlooked when designing any COVID-19 related policies.

### 3.2 Service activities

Patient organisations offer service activities in the form of information and support and play an important role in providing access to high quality information for public and patients. This information includes leaflets, websites, internet chat rooms and member networks. Support for members can include counselling

sessions for example. These various modes of service provision are often integral to the reach and impact of these organisations. COVID-19, and the introduction of lockdown and social distancing measures, impacted on the provision of these services significantly, such as the pause of in-person walk-in counselling sessions for patients. To mitigate the impact, ‘Bowel Cancer – UK’ began offering online counselling sessions, monthly webinars and initiated a new program called ‘ask the expert Q&A’, which helps provide clarity to those affected by bowel cancer during COVID-19.

### 3.3 Policy related activities

Jones, Baggott, and Allsop (2004), argued that campaigning, influencing national health policy, and further policy-related activities were regarded as crucial to patient organisations. Networking with civil servants, lobbying parliament, responding to enquiries from the media, and actively seeking publicity were some of the policy-related activities listed by patient organisations. In addition, most cancer patient organisations initiate and take part in campaigning for screening, early diagnosis, and raising awareness. The campaigning activities are often accompanied by active media participation and the strategic use of political contacts to ensure wide exposure. Since policymakers can only consider a number of issues at one time, they must prioritize some and pay less attention to others.

As an example, Pancreatic Cancer Action has ensured their services, which are advocacy focused and aim to raise awareness of the symptoms of pancreatic cancer, remain at the heart of their strategic response to mitigate the impact of COVID-19. Given that pancreatic cancer suffers from an extreme lack of awareness and funding (Pancreatic Cancer Action, 2022), during COVID-19 they have worked with NHS England to protect cancer patients and ensure the impact on the services was minimal by consistently lobbying and by providing cancer diagnosis services and treatments as normal. They have also advocated for cancer treatments to be provided while minimising the time patients with cancer spend in hospital treatments, recommending



that patients be able to consult their hospital teams by telephone, as well as by having their blood tests done at their local GP surgeries to minimise risks of them contracting COVID-19.

Cancer patient organisations have sought to focus attention on the issues concerning their members by appealing directly to public bodies and Government and questioning the existing approach or appealing to the public. Bowel Cancer UK mainly campaigns for early diagnosis and access to best treatment and care. However, during the COVID-19 pandemic, cancer patient organisations had to quickly demonstrate the damage and impact of COVID to policymakers to try and address the problems caused by it. For example, many organisations warned the government of a debilitating cancer epidemic that was occurring behind the scenes, noting that ‘cancer will not wait for COVID-19 to pass’ and have joined One Cancer Voice in calling on NHS England, NHS Scotland and both governments respectively to restore those cancer services paused during the pandemic (Cancer Research UK, 2020).

#### 4. DISCUSSION

COVID-19 has affected all areas of the health service, and with the primary focus of the world understandably geared towards tackling the pandemic, there is a significant risk that the subsequent impact on cancer services, on late diagnosis and delayed treatments, will trigger a potential cancer crisis. Cancer patient organisations, such as those discussed above, are at the forefront of this battle as they advocate for patients by promoting patient participation throughout the different stages of the policy making and service design/delivery processes.

This brief has explored how some patient organisations have responded and adapted to the impact of the pandemic as they try to maintain their, albeit reduced, advocacy role. However, with organisations having to ensure their survival and guarantee their continued work, due to lack of funding and reduced staff, advocating for the patients in health policy making and service design and delivery is under

risk. Lessons need to be learned so that in the event of any future pandemic or significant health event, cancer patient organisations are able to maintain their voice in decision-making.

#### 5. WHAT NEEDS TO BE DONE/ RECOMMENDATIONS

- As the government designs and drafts more policies to combat COVID-19 and its impact, the importance of cancer patient participation, via patient organisations, in the design of these is vital. Patients’ voices need to be included at the heart of the policy making process and not as an afterthought . Learning from the efforts of the Scottish Government’s Cancer Policy Team which meets on a weekly basis to ensure patients collective voice is heard and incorporated into policy designs, governments are encouraged to set up Patient Policy Teams in general and Cancer Policy Teams in particular. Such policy teams would be directly involved in policy design and policy making.
- Patient organisations have to ensure their survival and guarantee their continued work to act as advocates for patients in health policy making. The government needs to provide financial support to ensure their continued operation . As the role of organisations from the voluntary health sector increases in health care provisions, governments should offer grants and subsidies from the health and social care budgets and explore public private partnerships opportunities to supplement budgetary restrictions. If not, progress on bringing patient voices to decision-making tables could be reversed or left out entirely. It is in this context that the power of collective patient advocacy is needed more than ever.

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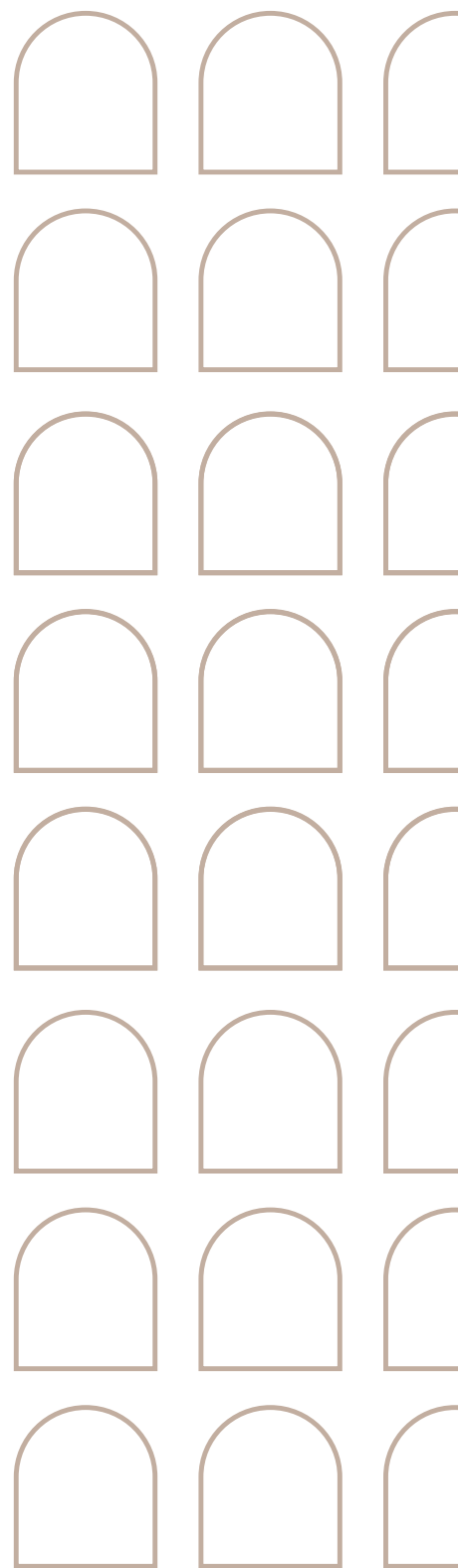
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The European Commission supports the EUI through the European Union budget. This publication reflects the views only of the author(s), and the Commission cannot be held responsible for any use which may be made of the information contained therein.

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**doi: 10.2870/120026**  
**ISBN: 978-92-9466-171-5**  
**ISSN: 2600-271X**  
**QM-BA-22-012-EN-N**

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