

<b>Meeting</b>	<b>Peninsula Cancer Alliance Board 22 July 2020</b>
<b>Title</b>	National Patient & Public Voices Forum Update
<b>Author</b>	Yasmin Clapp, Board Lay Member
<b>Agenda Item</b>	<b>Item 6</b>
<b>Summary</b>	
<p>Since the last Board Meeting, the Patient &amp; Public Voices (PPV) Forum has been asked to comment on some key pieces of NHSE &amp; NHSI guidance for NHS Cancer Services. The Peninsula Cancer Alliance representative on the forum would like to provide the Board with a short description of the role of the forum and what it has been discussing during the Coronavirus Pandemic 2020.</p>	
<b>Recommendation</b>	
<p>The Board is asked to note this feedback from its Lay Member and acknowledge the contribution they have recently made to improving care for cancer patients during the Coronavirus Pandemic 2020 through their participation in the National PPV Forum.</p>	

## 1. Background

Yasmin Clapp is one of twenty-three Young Ambassadors for **The Brain Tumour Charity**, raising awareness of symptoms and treatment and supporting other young adults going through similar experiences. The charity lead on and fund the **HeadSmart** brain tumour awareness campaign for children and young adults.

She became a member of the PPV Forum on 16<sup>th</sup> January 2020.

## 2. National PPV Forum

### 2.1 Remit (Terms of Reference)

The forum forms part of the governance structure of the NHS Cancer Programme and helps to ensure that nationally led projects are informed by and deliver for patients.

*“Forum members will play an essential role supporting our national team to obtain service user, patient and/or carer/family perspectives, and shape our projects.”*

NHS Cancer Programme, 2019.

The forum is chaired by a PPV member. The Chair represents the forum in internal and external meetings and acts as the main point of contact for the NHS Cancer Programme leadership: the National Cancer Director and Cancer Programme Director (Source: PPV Forum Members’ Application Form, 2019).

### 2.2 Role of a PPV Forum Member

The role of a forum members is to:

- champion the patient, service user, carer and family perspective, to help the NHS Cancer Programme continue to consider and prioritise the needs of patients and the public;
- provide advice on the design of new national Programme systems, policies, procedures and guidelines;



- build their understanding of the NHS and the Cancer Programme – through regular contact with the Patient and Public Engagement (PPE) leads for their local Cancer Alliance and the NHS Cancer Programme.

Source: PPV Forum Members' Application Form, 2019.

### **3. Forum activities during Coronavirus Pandemic 2020**

#### **3.1 Shielding Guidance feedback requested by NHS Cancer Programme (Professor Peter Johnson), four question survey and videoconference held on 9<sup>th</sup> June 2020**

##### **3.1.1 Summary of feedback from forum members on original shielding guidance**

###### **General**

Members felt that key stakeholder groups, including charities, clinical teams and even NHSE NHSI had been excluded from discussions regarding the guidance. Shared-decision making was called for.

###### **Communication**

Since the initial clear guidance that patients were warned was coming, the guidance had been unclear, and members of the shielding population had felt left out by the daily government briefings.

Some members suggested the guidance was badged as advice rather than sounding like instructions.

###### **Shielding List & Letter**

Members were concerned that the list of people who needed to be shielded had not been updated since first released. This led to a loss of confidence in the original list.

Members called for stratified shielding guidance for different conditions and different levels of risk. For example, guidance for how to shield when you have young children.

Members of the shielding population wanted to be told more about their personal level of risk.

They also wanted to know, what would be considered 'best' and what would be considered 'good' practice so there was a flexible approach to allow for individual (family/ household) circumstances.

###### **Government support/ support**

Members wanted more advice in terms of what PPE they needed to obtain and financial support to obtain it.

The shielding experience is mentally very tough. Members wanted as much support with regard to their mental wellbeing as support to meet immediate needs such as food and medicines etc.

## **Employment**

This had been an area where advice had not been given in sufficient details in terms of employee rights and how to return to work safely.

### **3.1.2 Summary of feedback from forum members on most recent updated guidance**

There was no warning the new guidance was coming out which caused shock, distress and anxiety amongst the shielding population. The shielding population want more involvement in discussions and warning when new guidance is coming out.

There is concern the new guidance is not rooted in the science, a lack of confidence.

The shielding population want sufficient information that they feel they as individuals with different risk levels to other shielding individuals can follow the new guidance.

There needs to be more advice around specific activities such as dealing with groceries, shopping.

Members want more advice and guidance for the non-shielding population so they can act safely in public places.

## **3.2 “Cancer diagnosis / support with pathways via the COVID-19 with Safety” videoconference led by Rapid Diagnostic Centres Team held on 11<sup>th</sup> June 2020**

### **3.2.1 Summary of feedback from forum members on the document entitled: ‘Cancer Diagnostic Services During Covid19’**

The following has been taken from a ‘You Said, We Did’ document circulated to PPV Forum members:

- Is there somewhere to sign post to some guidance on treatment provided to children and young adults or those with learning disabilities. To know what support is available to them during COVID19.”
- The document needs to highlight that communication is key. The patient should be told what is happening at each stage regardless of situation. For example, if an appointment is cancelled, they should be told why this was and when they should expect a follow up. It is important to provide reassurance to patients.
- The document needs to make sure that considerations for patients who are not able to have virtual appointments are made. And that sometimes face to face is necessary.
- The psychological / practical support side of the patient’s journey needs to be pulled out more as it is heavily focused on the physical side.

- Could the document highlight that some patients will have to use public transport to be able to get to a Covid-protected site and that travel distance needs to be considered and expectations realistic. Also need to consider that some patients do not have access to a mobile to be called in when waiting outside for their appointment.
- Need to make sure that this messaging gets out to GPs as some patients feel that their GPs do not want them to contact them at the moment.
- The ask for patients to self-isolate for 14 days is potentially burdensome and could stop some attending an appointment. Is there a need for this when they are going to be tested for Covid19 beforehand?
- Can an emphasise be put on that sites are Covid protected as some older patients are worried about attending and having access to facilities such as toilets.
- Is there any guidance on whether older patients or those with learning disabilities are able to have someone accompany them?
- Is there scope to do some treatments on the same day? Not just tests.

Source: You Said, We Did document, PPV Forum Feedback, National Cancer Programme 8<sup>th</sup> July 2020.

#### **4. Patient and Public Voice Partners Pilot Training Course 28th and 29th July 2020**

PPV Forum members have been offered the opportunity to take part in a pilot of the now virtual PPV Member 'Influence and Impact' Course. Following the pilot, participants will be asked to provide feedback which will help shape the finalised programme.