

DRAFT PATIENT SUPPORT TOOL

Introduction note:

In preparation for the workshop, we have developed this draft document for you. It outlines the questions that some patients might have at different stages of the cancer pathway - from being referred by their GP for investigation and tests, through to specialist services if they have a cancer diagnosis.

In the workshop we want to work with you to develop this draft. We want to make sure that we create a resource together to support people having tests for cancer or have been diagnosed with cancer.

No.	KEY transition points in the generic cancer pathway for patients	Patients control: What does a patient need? What can they ask?	ADDITIONAL: Information/Examples
1	At point of referral into urgent suspected cancer pathway	<p>When will my appointment take place?</p> <p>What if I don't hear about my appointment?</p> <p>What format and who will tell me?</p> <p>Will I have a consultation first or will it be straight to test?</p> <p>What can I expect to happen at the appointment?</p>	<p>e.g. expect an appointment in under 2 weeks.</p> <p>The available formats include - face to face, telephone, video call</p> <p>Straight to test pathway - you bypass an initial consultation and are booked into specific test/or tests for your symptoms</p> <p>e.g. Can I bring a relative or have a translator booked?</p>
2a	At first clinical consultation (HCP led e.g. doctor/clin nurse spec etc)	<p>What can you tell me about the suspected problem?</p> <p>What are the next steps in the investigation process? I may need further support to do this?</p> <p>Can I have some more information?</p> <p>How long will this process take?</p> <p>How do I contact the team if I need to?</p> <p>Is there an online patient portal where I can see my records to support me on my hospital journey?</p>	<p>e.g. site specific information</p> <p>e.g. email or telephone number of department e.g. carer, family member, friend etc e.g. leaflet</p> <p>e.g. department email? phone number? Note: more than switchboards number.</p>
2b	If first appointment is straight to test	<p>What does this actually mean?</p> <p>How do I get my test results?</p> <p>How long will this process take?</p> <p>How do I contact the team if I need to?</p> <p>Is there a patient portal where I can see my records to support me on my hospital journey?</p>	<p>e.g. Will someone call me to tell me?</p> <p>e.g. department email or named navigator</p>
3	Investigations	<p>Do I need to prepare for the test?</p> <p>Are there any after effects?</p> <p>How will the results be conveyed?</p> <p>How long does it take?</p> <p>Who do I contact if results are not communicated?</p> <p>How do I let you know if I need to rearrange an appointment, if an unforeseen circumstance arises?</p> <p>How will you let me know if I have cancer or not?</p>	<p>e.g. information leaflet for the specific procedure</p> <p>e.g. email for the imaging department.</p>
4	If further investigations are needed:	<p>Why are more tests needed?</p> <p>Where and when will these be conducted?</p> <p>How will I get the results?</p> <p>How long does it take to get results?</p> <p>Who do I contact if results are not communicated?</p>	
5	DIAGNOSIS	<p>What have you found out so far about what is wrong with me?</p> <p>How will you let me know if I have cancer or not?</p> <p>This process is making me feel worried and I feel I need additional emotional support - where can I look to for this?</p>	<p>signpost: https://www.samaritans.org/ or speak to your GP</p>
	A.1. Negative cancer diagnosis - Not cancer: No pathology found.	<p>I have ongoing symptoms - what can I do?</p> <p>Who will continue my care?</p>	
	A.2. Negative cancer diagnosis - Not cancer: Significant other pathology found.	<p>I don't have cancer but I have something else, what does that mean for me?</p> <p>Who do I need to see about this condition?</p> <p>How will I get there?</p> <p>How do I find out more in the interim?</p>	<p>e.g. signpost to relevant information</p>

	B. A Cancer Diagnosis is made	<p>What does this mean for me? What are my options? How can I make the best decision for me?</p> <p>What are the next steps and how soon do these occur? Where will the treatment take place? Where can I get more information Can I choose between virtual and in-person appointments?</p> <p>I may need emotional support to get me through this process, where can I go?</p>	<p>e.g. signpost to resources and touch on pre-rehabilitation.</p> <p>e.g. signpost to Macmillan</p> <p>https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotions-and-mental-health</p>
6	MDT discussion	<p>What is this part? How do I get feedback on this step?</p>	
7	Decision to TREAT	<p>Can the cancer be cured? What are my treatment options?</p> <p>I would like support tools to understand what is best for me?</p> <p>I need to understand the commitment and what is required for the treatment to take place.</p> <p>Will the treatments offered affect my ability to work or do my usual daily activities?</p>	<p>e.g. Shared decisionmaking tools to support patients</p> <p>https://www.macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/questions-to-ask-your-healthcare-team</p>
8	Treatment process	<p>Where will I have the treatment? Can I choose where to have treatment? What does treatment involve? What are the side effects of the treatment? and for how long? If experience side effects what can I do and who can I speak to?</p>	<p>e.g. local hospital or specialist centre</p> <p>Short term side effects and more long term ones</p> <p>e.g. cancer nurse/oncologist/GP</p>
9	Inter-trust referrals for further specialised	<p>Why am I being transferred? Where I am being referred to? Will they have information about me? How can I find out more?</p>	
10	Inter-trust referral back for continuation of care	<p>What do I need to continue with at my referring hospital? When will I be seen? Will they have information about what happened at the specialised trust?</p>	
11	Treatment Review	<p>Will there be more treatment? Has my cancer been cured? I would like to have a HNA and Treatment Summary What signs and symptoms of recurrence?</p> <p>Do I need ongoing monitoring or checks re my cancer? How do I get support for any ongoing symptoms related to my treatment? What information do I need to have about my treatment journey?</p>	
12	Discharge and community care planning (could be over a series of encounters)	<p>When will my hospital care end? Am I being discharged for good?</p> <p>How will I continue to get support once I am discharged? How do I get help if I have further questions? What support can you give me to help me continue my life?</p> <p>Do I need ongoing monitoring or checks re my cancer? What information do I need to have about my treatment journey? How do I get help if I feel sick again?</p>	<p>e.g. Clarity on discharge plans - from personalised</p> <p>e.g. The GP practice is well placed to continue support in the community. They can conduct a cancer care review once you are ready.</p> <p>e.g. Health and wellbeing events</p> <p>e.g. regular relevant investigation</p> <p>e.g. The discharge summary or treatment summary</p>