

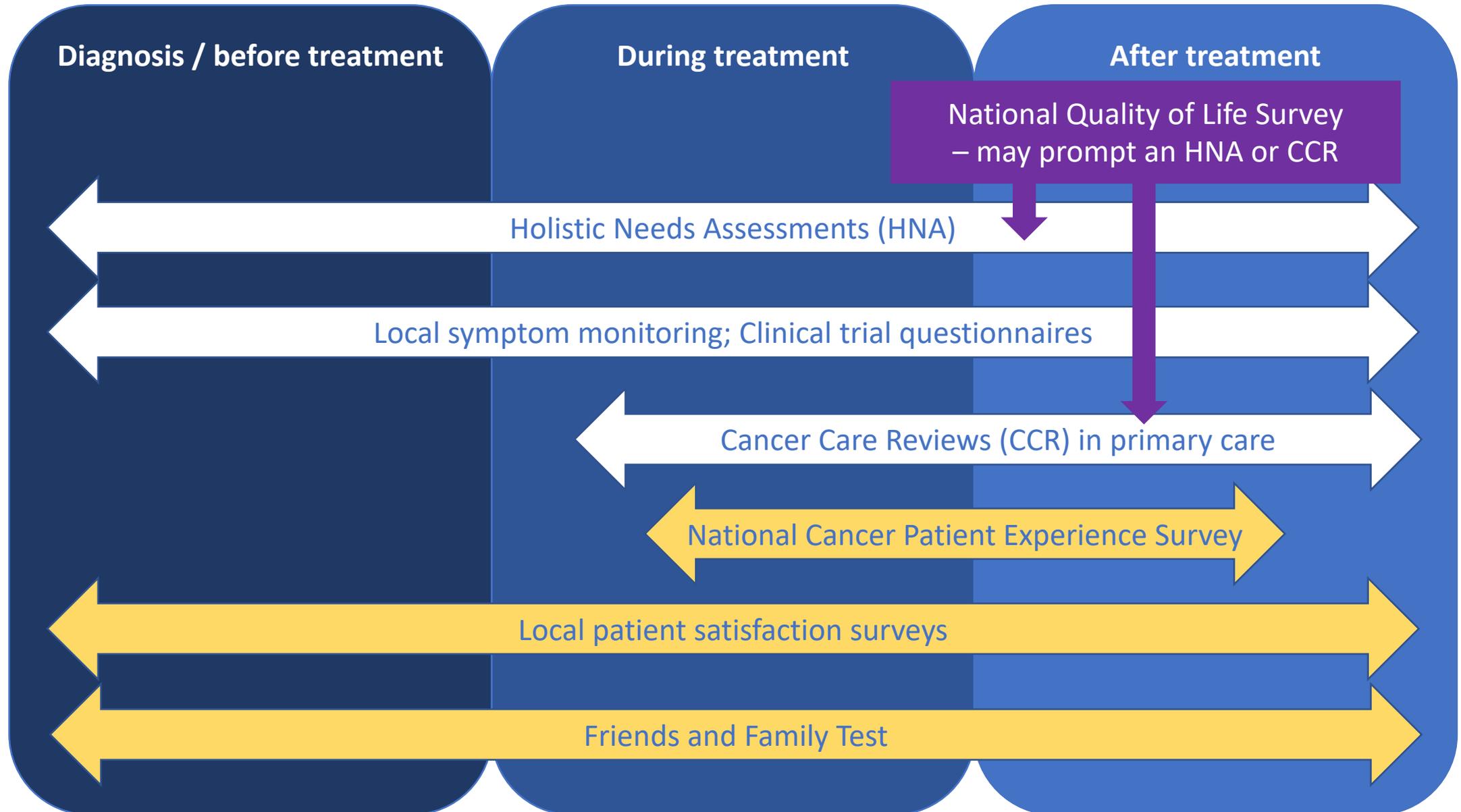
The purpose of these slides is to help staff* who regularly speak with cancer patients in England to:

1. understand how the Quality of Life survey differs from other surveys and tools that are used to gather patient-reported information.
2. explain to patients how the QoL survey fits in alongside other surveys or 'tick box' forms that they may be given after their cancer diagnosis, and why it is very important that they complete the QoL survey if they possibly can.

* Cancer team members (doctors, nurses, AHPs, cancer support workers, receptionists, clinic 'welcome' volunteers etc), cancer information centre staff, cancer charity helpline staff, cancer charity websites, primary care team members



When are questionnaires and reviews usually carried out with cancer patients?



	Differences between questionnaires that cancer patients may receive in England 2020			
	Holistic Needs Assessment (HNA)	Cancer Quality of Life Survey	National Cancer Patient Experience Survey	Other 'Symptom' or 'Satisfaction' Surveys
What is it?	A conversation with a member of your healthcare team to discuss all your concerns and what you need.	A short, nationwide, 10-minute survey asking about your overall emotional, physical and social wellbeing.	A nationwide survey asking about your satisfaction with the care you have received.	Locally run surveys, for example, run by university researchers, cancer charities, or as part of a clinical trial.
When will I be asked to take part?	<i>You can be offered, or you can ask for, an assessment at any time.</i> It is likely that a member of your cancer care team will offer an HNA at least once. Useful time points are soon after diagnosis, at end of treatment, and whenever your circumstances or needs change. You can have an HNA as many times as you like.	<i>This is a one-off survey.</i> You will receive an invitation to take part through the post. You will be invited to take part around 18-months after you were first diagnosed with cancer. When it first launches, only a sample of people with certain cancers will be invited to take part. By 2022 it is expected most people will be invited.	<i>This is a one-off survey</i> that usually runs every year for three months. You might be asked to take part, but not everyone will be. Only people who have been treated for cancer during the 3-months that the survey is run are asked to take part.	<i>These can be one off, or surveys that are repeated many times during your treatment.</i>
Example question:	Do you have any physical concerns that you want to talk about?	How would you rate your overall health in the past week?	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	<i>Questions may be more targeted towards a particular treatment or cancer type and be quite detailed.</i>
How do I give my answers?	Various options include: <ul style="list-style-type: none"> - On an electronic tablet in the clinic - Online - Paper, possibly in advance of a hospital appointment - Verbally - questions asked over the phone or in a clinic appointment 	Online form Paper format can be provided	Paper Online option	Paper Online Telephone
What happens to my answers?	Your answers will be discussed with you and used to agree a personalised care and support plan to ensure that you get the help and support you need through your cancer journey.	Your answers will be analysed along with everyone else's to help to build up a national picture on quality of life outcomes for people diagnosed with cancer. [It is planned that] Your answers will be given back to you in a format that helps you to understand how your quality of life compares to other people in a similar position to you.	Your answers will be analysed along with everyone else's to help to build up a national picture of how people feel about the quality of the cancer care that the NHS provides, and how satisfied people are with their care (called 'patient experience').	This depends on who is running the survey. For example, a survey used in a clinical trial might help to decide if a new treatment is causing bad side effects in too many patients. A survey run by a charity might help the charity decide, for example, what is most important for them to campaign about.
How are my answers useful to me, to other patients and to the NHS?	An HNA can help you to express what is concerning you the most at that moment, and to work out if you need any support - thus enabling your health care team to provide that support. In some places, HNA responses are analysed to see what people's top concerns are.	Filling in the survey could prompt you to notice something you are worried about. If so, you can speak to your cancer care team, and perhaps go on to have an HNA or a review with your GP. The information collected in the survey will help the NHS to work out where it needs to better support people to live well after a cancer diagnosis.	The information about cancer patient experience across England will help the NHS to work out where it should drive local and national improvements in quality of cancer care provided when someone is being diagnosed and receiving cancer treatment.	The results can help to inform the type of treatment or services provided.