

**NATIONAL INSTITUTE FOR HEALTH AND CARE
EXCELLENCE**

INDICATOR DEVELOPMENT PROGRAMME

Consultation report

Indicator area: Cancer

Consultation period: 25 June – 15 July 2020

Date of Indicator Advisory Committee meeting: 04 August 2020

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Summary of indicators included in the consultation

ID	Indicator	Evidence source
IND 2020-82	The percentage of patients with cancer, diagnosed within the preceding 12 months, who have had a discussion within 3 months of diagnosis about the support available from primary care	Patient experience in adult NHS services NICE guideline CG138 recommendations 1.1.1, 1.3.4 and 1.3.5
IND 2020-83	The percentage of patients with cancer, diagnosed within the preceding 24 months, who have a patient review using a structured template within 12 months of diagnosis.	Patient experience in adult NHS services NICE guideline CG138 recommendations 1.1.1, 1.3.4 and 1.3.5

IND 2020-82: Cancer: support available from primary care

The percentage of patients with cancer, diagnosed within the preceding 12 months, who have had a discussion within 3 months of diagnosis about the support available from primary care.

Rationale

Current QOF indicator CAN003 which focuses on review at 6 months has high levels of personalised care adjustment reporting (formerly known as exception reporting). Anecdotal feedback on the current indicator suggests that the timing of the review 6 months post diagnosis is inappropriate for many patients especially in relation to understanding the support available from primary care. This indicator aims to encourage GP practices to proactively make patients aware of the support available from their GP and wider practice team soon after their diagnosis and how this can complement the care they are receiving in secondary care. The intention is to facilitate early and supportive conversations and ensure patients are aware of what help is available.

Summary of consultation comments

Stakeholders generally welcomed the inclusion of this indicator, commenting that it will have a positive impact on health outcomes, raise patient awareness of what support is available from primary care and increase understanding of care in general. They highlighted that:

- There is potential to link with holistic needs assessments undertaken in secondary care, existing support roles and support transitions of care
- Discussions could be effectively done remotely.
- Meaningful coding and having a defined output such as a care plan would help prevent tick-box approaches.
- This is being done effectively already in some areas.

Stakeholders raised issues around implementation such as GPs not receiving timely information on diagnosis, a need to define what offers of support should be made and to specify how the contact should take place. Some stakeholders did raise that patients could be overwhelmed by secondary care appointments and may not welcome an additional appointment at this time, and that some patients may not be able to take part in discussions by phone/digital means. They also highlighted barriers in practice capacity.

Consultation question: Is 3 months an appropriate timeframe to discuss with the patient the support available from primary care?

Many stakeholders thought the timeframe was appropriate and highlighted that:

- The discussion should be offered periodically if not initially accepted.
- Where diagnosis information is slow in getting to GPs the timescale would ensure discussion within a meaningful timeframe.
- It would give patients knowledge of support available at the beginning of treatment.
- It would give GPs enough time to prepare for the discussion.

Some stakeholders did not think the timeframe was appropriate and highlighted that:

- It would not align with health needs assessment hospital pathways.
- It would be difficult to arrange a face to face appointment in this time.
- The window to have the discussion should be wider to give patients time to understand their diagnosis and secondary care appointments.
- 6 months may be more appropriate.

IND 2020-83 Cancer: 12 month review

The percentage of patients with cancer, diagnosed within the preceding 24 months, who have a patient Cancer Care Review using a structured template within 12 months of diagnosis.

Rationale

One-year survival from cancer increased by almost 10% between 1999 and 2014, while mortality rates from cancer have been decreasing. The increasing number of cancer survivors has led to an increase in the number of people requiring follow-up care, monitoring and management.

Current QOF indicator CAN003 which focuses on review at 6 months has high levels of personalised care adjustment reporting. Anecdotal feedback suggests that for many patients and clinicians the current 6 month window for the review is inappropriate for many people and does not allow for the timing of the review to be personalised to each patient's treatment plan. This indicator presents an alternative timepoint which will give greater flexibility to general practice to perform the review at a time which is more appropriate for the individual patient and may be linked to key events such as the receipt of an end of treatment summary from the hospital cancer team.

A national template could be based on the Macmillan cancer review which recommends a discussion of the diagnosis and recording of cancer therapy, an offer of relevant information, medication review, benefits counselling and recording of a carer's details.

Summary of consultation comments

Stakeholders generally welcomed the inclusion of this indicator, commenting that it would also be an opportunity to address other cancer risk factors. They highlighted that:

- Cancer care reviews should occur annually or there should be multiple reviews post-treatment. It was also suggested that a review be conducted after diagnosis as well.
- This should be seen as a 'health needs assessment' and have less of a clinical focus. Additionally health needs assessments done at the end of treatment may also cover some of the review content.
- It could be done remotely, although face to face would be ideal.
- It could be conducted over more than one appointment and with the input of more than 1 health professional.
- It would benefit from having a defined output such as a care plan.
- It would link well with a discussion of primary care support at 3 months.

Stakeholders raised issues around implementation such as requiring training, needing a definition of the review contents, and questioning when the 12 month timescale should begin. Some stakeholders raised that the focus should be on the number of reviews a patient gets rather than a time scale, and one felt that this was the role of a cancer specialist. They also highlighted that a one size fits all review would be bad for some patients, and that some may find it difficult to take part remotely or may require additional consideration of their communication needs.

Consultation question: Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients?

Many stakeholders thought the timeframe was appropriate and highlighted that:

- There may need to be scope for flexibility or personalisation of the timing.
- The longer timeline improves the ability to personalise the timing compared to 6 months.
- Patients may be more receptive within the revised timeline.

Some stakeholders did not think the timeframe was appropriate and highlighted that:

- 12 to 18 months would be more feasible.
- 12 months may be too long to wait for some patients, for example those with complex needs.
- It would be best linked to discharge from secondary care rather than a timescale.

Consultation question: In future, should we explore linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis?

Many stakeholders thought linking to end of treatment summaries was appropriate and highlighted that:

- They should be termed 'treatment summaries' to include cancer patients that do not have a definitive end point to their treatment.
- This would present an opportunity to arrange further care.
- That it should still take place at 12 months post-diagnosis.
- This would improve integration between primary and secondary care.
- This would provide context to the cancer care review.

Some stakeholders did not think linking to end of treatment summaries was appropriate and highlighted that:

- End of treatment summaries are not fully embedded/universally available.

- That the timing should be personalised and not linked to a treatment milestone.
- Reviews should be ongoing.

Consultation question: Is the inclusion of a national template useful in ensuring consistency and improving outcomes for patients?

Many stakeholders thought inclusion of a national template was appropriate and highlighted that:

- It could support personalisation and improve patient outcomes.
- The existing Macmillan template would be suitable.
- It would add consistency to reviews by providing a guide for GPs.
- It should be auditable to ensure it was conducted meaningfully.
- It would help avoid duplication with secondary care discussions.
- It would need to align with any coding.

Some stakeholders did not think inclusion of a national template was appropriate and highlighted that:

- This would be better achieved locally.
- It could lead to a tick-box approach.

Appendix A: Consultation comments

ID	Proforma question no.	Stakeholder organisation	Comment
		Question 1: Do you think there are any barriers to implementing the care described by these indicators?	
IND 2020-82	1	Cancer Research UK	Barriers - GP insight tells us that often GP practices do not receive timely information regarding a patient's diagnosis, treatment plan, etc and so they are unable to respond to patient queries. Although this proposed indicator is about support from primary care, it cannot be divorced from the more general information and support role that patients want post cancer diagnosis, and insight suggests patients often turn to their trusted GP for this.
IND 2020-83	1	Cancer Research UK	Barriers - the evidence from the East of England Cancer Alliance which has funded Cancer Care Reviews shows that even incentivising primary care does not necessarily improve results. The Cancer Alliance funded practices on a per case basis, but only obtained about 50% completion and some practices dropped out. Instead, what makes a difference is having motivated nurses given the time to do Cancer Care Reviews properly.
IND 2020-83	1	Cancer Research UK	Barriers - it is much easier to provide signposting for a specific tumour type where a range of support services exist and are well co-ordinated, and much harder to do this generically in a 'one-size' fits all manner. This barrier would need to be taken into consideration
IND 2020-82	1	North East London Cancer Alliance	<ul style="list-style-type: none"> · The willingness and capacity of primary care to deliver CCRs without resource or financial incentives. · Lack of accredited training. · Patients should also be provided with information on what to expect from a CCR which isn't currently being provided as standard. · Inconsistency in coding and communication between primary and secondary care. <p>Guidance on coding is available: https://www.healthylondon.org/wp-content/uploads/2019/07/Guidance-on-clinical-coding-of-cancer-patients-in-primary-care.pdf</p>

ID	Proforma question no.	Stakeholder organisation	Comment
		Question 2 : Do you think there are potential unintended consequences to implementing/ using any of these indicators?	
IND 2020-82	2	Cancer Research UK	Unintended consequences - this is a very broad subject and it would be important to define 'what good cancer support looks like' or give examples alongside the indicator, so that GPs know what exactly is meant by this. Otherwise, there will be different interpretations and actual support offered to patients will vary. The unintended consequence will be that the patient experience will not necessarily improve despite the investment.
IND 2020-83	2	Cancer Research UK	Unintended consequences- Local pilots in Pennine Lancashire have previously been positive from a process point of view, along with anecdotal satisfaction, rather than proof of quality. Would want to understand the evidence behind the improvement of patient experience/outcomes.
IND 2020-83	2	Cancer Research UK	Unintended consequences - Implementing Cancer Care Reviews has a restrictive (medical) aspect regarding who delivers this and what is discussed. We would recommend using the terminology of a 'health needs assessment' along the lines of the ones delivered in hospital within 3 months. This will then open out the intervention to the wider team in practice to support the patient and to look more holistically at the patient.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	2	Cancer Research UK	<p>Unintended consequences - We agree with the 12-month timeframe but also that cancer care reviews should be annual. One unintended consequence of this proposed indicator is that primary care considers this as a one-off requirement for reviewing patients' cancer care, whereas this must be ongoing. Long term cancer must be regarded as a long-term condition (which would align with the revised RCGP Curriculum 2019) – especially as more patients live with cancer at 1, 5 and 10 years, and 50% people likely to have cancer in their life time. If cancer were regarded as a long-term condition with an annual review and included as a QOF indicator, this would drive change. The benefits would include:</p> <ul style="list-style-type: none"> · Ensuring patients are included on practices cancer registers secondary to improved coding. · Practices developing recall systems, to ensure all patients are offered a review – as currently happens with other chronic illnesses. · Clinics run by trained nurses and supported by Medical team. · The training of practice nurses and medical team regarding a new area of medicine- late effects of cancer and consequences of cancer treatment. · Improved patient care and support, hopefully enabling patient to present earlier with concerns of recurrence etc. · Improved patient experience. · The opportunity to discuss and plan, End of Life care for those patients living with cancers being treated by palliative approach. · Perhaps also better communication between primary care nurses and secondary care clinical nurse specialists, to enable primary care to get prompt advice. <p>The opportunity to change the traditional secondary care follow-up model</p>
IND 2020-82	2	North Central London Cancer Alliance	<p>Risk of a tick box exercise being conducted to meet the 3-month target. To circumvent this, suggest that meaningful coding is utilised to document the ask of primary care. This will improve quality of the reviews and assist to standardise a high-quality intervention.</p>
IND 2020-82	2	North East London Cancer Alliance	<p>Inequality around the offer of a CCR particularly if relevant information from secondary care, such as notification of cancer diagnosis, review of the patient's HNA, a Treatment Summary at the end of active treatment or a discharge letter, is not sent/received by primary care.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
		<p>Question 3: Do you think there is potential for differential impact (in respect of age, disability, gender and gender reassignment, pregnancy and maternity, race, religion or belief, and sexual orientation)? If so, please state whether this is adverse or positive and for which group.</p>	
IND 2020-82	3	North Central London Cancer Alliance	Adverse differential impact: If digital approaches are implemented e.g. text or email, this will exclude those who do not have access to, or are unable to utilise, digital technology
IND 2020-82	3	North East London Cancer Alliance	No differential impact perceived as long as format of CCR is personalised for the patient i.e. telephone, face to face, digital. The mode of CCR should be agreed with the patient. This includes having carers and family members involved in the CCR.

ID	Proforma question no.	Stakeholder organisation	Comment
		<p>Question 4 : If you think any of these indicators may have an adverse impact in different groups in the community, can you suggest how the indicator might be delivered differently to different groups to reduce health inequalities?</p>	
IND 2020-82	4	North Central London Cancer Alliance	<ul style="list-style-type: none"> · Offer a suite of coded options that reach out to individuals when they are first diagnosed · Ensure this is linked to first language and that there is an option to code for factors such as offering interpreter
IND 2020-82	4	North East London Cancer Alliance	<ul style="list-style-type: none"> · Adverse impact: as above, the CCR should be personalised to the patient and in a format that they are comfortable with; involving carers and family members as necessary.
		<p>General comments on both indicators</p>	

ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	All.Can UK	<p>In relation to IND 2020-82 and IND 2020-83 regarding the support that is available to people with cancer:</p> <ul style="list-style-type: none"> · All.Can UK believes it is imperative that people with cancer are offered regular touchpoints with healthcare professionals and that psychological support should be personalised to the needs of the individual as much as possible. This is very much in line with the findings of a report that is currently being developed by All.Can UK about the importance of placing the psychological wellbeing of people with cancer on an equal footing to physical health. · Each patient will require different levels of physical and psychological support and, as such, their care pathway should be tailored to their needs. The suggested timescales (i.e. within 3 and 12 months for IND 2020-82 and IND 2020-83, respectively) therefore may not be appropriate for all individuals and some patients may require support at a later date. For example, while we are supportive of the rationale for IND 2020-82, in so much that it aims to encourage GP practices to proactively make patients aware of the support that is available, we believe that this should be periodically offered throughout an individual's care journey and the indicator should therefore be extended or repeated to reflect this. · Psychological support for people with cancer should not be 'one size fits all'; to support the implementation of the NHS Long Term Plan, Cancer Alliances have been made responsible for working with NHS Trusts and primary care to offer personalised care interventions to people with all cancers by 2021. Furthermore, healthcare charities that are members of the All.Can UK Working Group and contributed to the development of the report into psychological wellbeing have signalled the importance of patient choice. All.Can UK believes that personalised interventions should be included within QOF indicators as a way to improve standards of care for patients and ensure they can choose the care that best suits them.

ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	All.Can UK	<ul style="list-style-type: none"> · Similarly, the evidence gathered for the development of our report has shown that there is a lack of screening for mental health concerns throughout the care pathway. Often, screening is undertaken just after diagnosis, but it would be more beneficial to repeat this process at key milestones within a patient’s care journey. Within the context of these indicators, it would be helpful to understand whether the timescales suggested (i.e. 3 months for IND 2020-82 and 12 months for IND 2020-83) relate to only one discussion or Cancer Care Review taking place or if these are deadlines for at least one conversation (i.e. QOF payments can be accessed after each discussion that occurs within the timeframe). · All.Can UK believes that emphasis should be placed on the number of consultations that are held to review cancer patients’ physical and psychological needs as opposed to there being a fixed time by which point a review must have been held. While increasing the timescale for IND 2020-83 will allow for greater flexibility, it could result in patients waiting longer for a Cancer Care Review and could therefore be detrimental to their care. We therefore believe that, if the indicator is extended to 12 months, it is important to reiterate that patients should be offered regular touchpoints within this timescale to ensure that they are aware of the support that is available to them. · In addition, we do not believe that Cancer Care Reviews should be attached to milestones within the care pathway (e.g. at the point of diagnosis or at the start/end of treatment plans) as this might not be appropriate for all individuals. Instead, patients should be made aware of the support that is available to them at regular intervals throughout their care journey.

ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	All.Can UK	<ul style="list-style-type: none"> · Furthermore, it is also worth noting that the post-treatment phase of cancer care can be one of the most volatile times for mental health and the period where the full psychosocial impacts of cancer and treatment can be felt most acutely. With this in mind, All.Can UK believes that Cancer Care Reviews should be offered to patients on a regular basis post-treatment to ensure that they are aware that mental health support is available. Therefore, the indicator should not only be applicable to the first 24 months post-diagnosis but should be extended or repeated. · Specifically relating to IND 2020-83 and the use of a structured template, All.Can UK would support the use of a template based on Macmillan Cancer Support's cancer review. We believe this would be a valid way to standardise the consultations that are held with patients. However, we are aware that the template might not be applicable to the varied needs of patients with all cancer types and it will therefore be important for healthcare professionals to be given training in this area to ensure that patients are given information about available support services. <p>By way of background, All.Can UK is a partnership between leading health charities and biopharmaceutical companies with a shared ambition for cancer patients to receive world-class, patient-centred care that is sustainable for the NHS to deliver. All.Can UK is led by a number of patient organisations from across the cancer community, who collectively make up the Working Group. The initiative is currently chaired by Rachel Power (Chief Executive, The Patients Association) who sits on the group's governing body, the Steering Committee, alongside Melanoma UK, Bowel Cancer UK and the two current Funding Partners: Bristol Myers Squibb (BMS) and MSD.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	City and Hackney CCG	<ul style="list-style-type: none"> · Need to clarify if CCR is to be done twice at <3m and <12m or would one <3m cover both · CCR good to be done early but some patients would not be able or happy to come within first 3m during the busiest time of their cancer care and wouldn't be fair to penalise GPs if they decline · Change wording to the "offer of". Could the first CCR <3m be a telephone review? · Many patients feel when hospital treatment ends they are "falling off a cliff" as hospital support suddenly stops so this would be a better time for primary care to step in and chance for management of long term side effects related to cancer/ cancer treatment · Not all cancer will have an "end date" for e.g. blood cancers are never discharged and so finding right time for each cancer may vary. · Should not depend on treatment summary from hospital as currently inconsistent. Although useful to have and guiding the conversation. There is often a lag between patient hospital care finishing and a treatment summary being completed and sent to GP and therefore could be a missed opportunity for support during that crucial time. · 12-18m would give more flexibility · As many patients have ongoing issues related to their cancer or treatment, could an annual cancer review be considered (like other LTCs) <p>National template is useful to guide conversation. Worry that it can become a tick box exercise for some practices and so auditing quality would ensure meaningful conversation. Would improve patient outcomes. Should allow for different health care workers e.g. social prescribers to complete the CCR</p>
General	n/a	Individual 1	<p>Cancer is a long term condition and the consequences of treatment and the impact on people's lives do not go away after a year therefore, it would be beneficial for patients and GP practices to have these yearly like the other long term conditions QOF reviews.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	Individual 6	<p>3 months is appropriate for first indicator of discussion re support from primary care, however, do you expect this to be separate from a CCR at 12 months? They would work better as separate criteria i.e. CCR at 12-18 months if you want to focus on the longer-term issues affecting people living with cancer.</p> <p>It makes sense to link it with treatment summaries but you would have to structure it so the denominator is the no. of treatment summaries received otherwise primary care will get penalised for the failure of 2y care to do treatment summaries.</p> <p>National template useful in benchmarking the expected standard of a CCR, especially if it links to resources</p>
General	n/a	Individual 11	<p>Laudable but what about low level cancers (if there can be such a thing) that require intervention and work from lots of healthcare professionals are these going to be forgotten?</p> <p>I am thinking about our dermatology service (County Durham) where we take photographs using a dermascope and send to colleagues in secondary care. These colleagues have been known to see patients based upon the photos and do excisions there and then and then notify us that it was cancer but has been excised and no further treatment is required.</p> <p>A missed opportunity to capture cancer care activity</p>
General	n/a	Individual 13	<p>This is a very blunt tool. Some cancer patients need lots of support and some do not. Some do not want the GP practice chasing around after them when they have appointments with surgeons, oncology, radiotherapy etc. Some need no follow – e.g. a patient with a completely excised squamous cell skin cancer. A one size fits all tick box exercise will do nothing to improve the care of patients who need support. Allow GP practices to follow the appropriate patients as they think fit and do not make them tick another box just to maintain income for the practice.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	Macmillan Cancer Support	<p>Background and context</p> <p>Macmillan estimates there are almost 3 million people living with cancer in the UK. We predict this number will rise to nearly 3.5 million by 2025, and 4 million by 2030¹. As the risk of cancer increases with age, more people will be affected by cancer in their lifetime. Improvements in treatment and diagnosis also mean more people are now living longer after their diagnosis. It is vital that the health and care system adapts to meet this growing and changing demand.</p> <p>Macmillan recognises that for many people, cancer is a long-term condition that is increasingly managed by primary care professionals. A study has highlighted that fifteen months after their diagnosis, patients had 50% more contact with their GPs than expected². The growing support provided to people with cancer by general practice has been recently recognised in the national policy agenda, including in the rollout of Universal Personalised Care³, the new GP contract and the development of new Primary Care Networks (PCNs)⁴, which identify an explicit role for PCNs in early cancer diagnosis.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	Macmillan Cancer Support	<p>The 2019 National Cancer Patient Experience Survey (CPES) highlights that people with cancer don't always receive full support from primary care. When people with cancer were asked if GPs and nurses at their general practice did everything they could to support them through their cancer treatment, 1 in 7 respondents said no, they could have done more⁵. That proportion has been growing in national CPES reports. Including cancer-related indicators in the Quality and Outcomes Framework is therefore a vital tool to raising the standard of care people with cancer experience in primary care.</p> <p>1 Analysis based on observed cancer prevalence in 2017 (2015 for Wales), published by the cancer registries for each nation in the UK. The relationship to complete cancer prevalence is derived from 2013 complete prevalence (Macmillan-NCRAS Cancer Prevalence Project). This is projected forwards using the UK growth rates in Maddams et al. (2012), resulting in an estimated 3 million in 2020, 3.5 million in 2025 and 4 million people in 2030 living with cancer in the UK. This includes all people who have ever had a cancer diagnosis; some people in this group may no longer consider themselves to be living with cancer.</p> <p>2 The Nuffield Trust, The use of health and social care by people with cancer, May 2014 available at https://www.nuffieldtrust.org.uk/research/use-of-health-and-social-care-by-people-with-cancer</p> <p>3 NHS England/NHS Improvement, Universal Personalised Care: Implementing the Comprehensive Model 2019 https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/</p> <p>4 NHS England and NHS Improvement/British Medical Association Update to the GP contract agreement 2020/21 to 2023/24 https://www.england.nhs.uk/publication/investment-and-evolution-update-to-the-gp-contract-agreement-20-21-23-24/</p> <p>5 National Cancer Patient Experience Survey report 2019 available at https://www.ncpes.co.uk/wp-content/uploads/2020/06/CPES-2019-National-Report_V1.pdf</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
General	n/a	NHS Sheffield CCG	<p>Undertaking a cancer care review at 3 months provides the person living with cancer an opportunity to think about their needs in more detail in primary care, once a person has been discharged from secondary care and following their holistic needs assessment, they can begin to understand the long term effects of cancer such as financial, work, emotional and family issues at 3 months they can discuss with their health care practitioner,(GP, Practice nurse or link worker) how their diagnosis has impacted on their life and plan forward, this can help them regarding how best their needs can be met.</p> <p>At 12 months this also meets the individual needs as usually their treatments have ended and gives the person with cancer more understanding of living with and beyond cancer in primary care. They can then reflect on their discussion with the healthcare practitioner at 3 months to establish if this has improved their holistic needs and this can then be re-assessed and updated</p> <p>A national template would be useful as it could improve patient’s experiences and outcomes by using a template as a prompt, ensuring no patient outcomes are missed. The template could also be audited and used on both on a National and local level.</p>
General	n/a	North East London Cancer Alliance	<p>There has been significant work across London to develop a 4-point model for holistic cancer care reviews. The model developed by the Transforming Cancer Services Team outlines where a patient could benefit from “touch points” by primary care while under the care of the cancer specialists at the hospital. The aim of the model is to support people with a diagnosis of cancer to self-manage. For some people, they may live with or beyond cancer for many years or decades. The link to the model developed by the Transforming Cancer Services for London is https://www.healthylondon.org/resource/cancer-care-review-tools/</p>
General	14 and 15	PC24 Social Enterprise	Yes
		General comments IND 2020-82	

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	British Medical Association	<p>The percentage of patients with cancer, diagnosed within the preceding 12 months, who have had a discussion within 3 months of diagnosis about the support available from primary care.</p> <p>We recommend that this indicator be amended to ensure patients are getting the right advice, from the right people, at the right time. Patients do need to know about support available from primary care, but in the first 3 months they can be saturated with information and preoccupied with arranging appointments, seeking investigation and having share dialogue about treatments outside of primary care. Their needs will also be different depending on the stage of cancer.</p> <p>We would support an amended version of IND2020-82: "...discussion within 12 months of diagnosis..." to give GPs the flexibility needed to cater to individual patients' needs.</p>
IND 2020-82	n/a	Coventry and Warwickshire Cancer Board	<p>In light of how we work post COVID I think it needs to be clear what the contact needs to be, for some a text with all the relevant info on things like local iapt would be sufficient, others may need a face to face review, this should be up to the clinician.</p> <p>Also, each patient is different, and some may be travelling a lot for appointments and not want to come to their GP surgery at the time so the link needs to be proportionate – a phone call may be sufficient</p>
IND 2020-82	n/a	Fosse Medical Centre	<p>Patient newly dx with Ca are feeling overwhelmed and bombarding them with even more info and yet another appointment to attend wouldn't be useful at all. They are being introduced to cancer charity nurses by secondary care and LOROS or Macmillan nurses do get in touch with us if anything is needed. The first 6 months of their treatment is heavily focused on secondary care – why involving primary care at that point if no need? In long term – once initial treatment completed – yes, but that should be after at least first 6-12 months from diagnosis.</p>
IND 2020-82	n/a	Individual 7	<p>I think it is really important for primary care to make contact with patients with new cancer diagnoses soon after diagnosis. This reflects our current practice at Yealm Medical Centre. We discuss all new diagnoses and then nominate a clinician to contact them. It would be good to specify that this can be telephone contact as patients do not want to attend the practice in this timeframe.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	Individual 9	<p>Firstly, I think it's great to see another Cancer measure being proposed for QoF, which could support the monitoring of the personalised care and support agenda.</p> <p>My concerns though however are that the potential for this to be tick box exercise. As with suggestion for use of a template for the cancer care review could this also be linked possibility to the health and wellbeing support checklist (in development by NHSE), although I haven't seen this yet (webinar on this taking place on 15th July) it may provide structure/aide memoire to the types of support that patients and their carers may find useful.</p> <p>This could also link to a holistic needs assessment which could help identify the patients support needs.</p> <p>Would be helpful to encourage a discussion with the secondary care teams to understand where primary care could provide initial support and guidance early on in the cancer pathways.</p>
IND 2020-82	n/a	NHS Lincolnshire CCG	<p>The response and comments outlined in this document have been submitted by Lincolnshire's Living With Cancer Programme as part of a coordinated and unified response on behalf of the programme, Macmillan GPs and Lincolnshire's Patient Co-Production group.</p> <p>Lincolnshire's Living with Cancer Programme has consulted with over 43 local GPs and has conducted over 140 patient interviews. The programme also works closely with a cancer patient co-production group who have supported this response. Where appropriate, key findings have been included in this feedback for questions 14-17 of the consultation document.</p> <p>Lincolnshire's Cancer co-production group unanimously agreed that receiving some form of contact from their GP/Practice, in the first 3 months following diagnosis, would be greatly valued. This could be a telephone call or letter to explain how the practice can offer support and to signpost patients to immediate and local resources (support groups, Macmillan website etc.).</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	NHS Lincolnshire CCG	<p>The group expressed that in some cases this was seen as necessary, particularly for those entering immediately onto a palliative or end of life pathway. As a group who have a lived experience of cancer it was stated that contact in the first 3 month should then be followed with a more formal CCR appointment within the following 12 months. In addition, this should be at a time that is most beneficial to the individual whilst considering the prognosis and specific cancer type that has been diagnosed (rarer cancers may need supplementary guidance and specific support).</p> <p>This was echoed from a Macmillan GP [quote] 'It's touching base after a diagnosis. Exchanging info and offering empathy and support while signposting to resources. Could be phone call/video/F2F as appropriate, maybe backed with written/emailed standard resource sheet. There aren't many diagnoses we don't know by two months'</p> <p>The Living with Cancer programme recognises that there are practices in Lincolnshire that make contact within the first 3 months of learning about a patient's cancer diagnosis. It has been reported that in doing so there are significant benefits; for instance, it starts a conversation with the patient about how the practice can offer support and what their role is as a GP. This however is not established in all areas across the County resulting in patients receiving significant and unwarranted variation in their experiences.</p> <p>The Lincolnshire Living with Cancer programme advocates a need for change within the existing QoF indicator CAN003, as there is currently a lack of clarity about what CCRs should include and how they are to be conducted. Without this, practices will often take the path of least resistance when complying with QoF indicators [Quote from GP]. There is a need to expand on protocols and guidelines to give structure and guidance to GPs and to support a more standardised delivery model. If indicators are changed to include contact within the first 3 months, clear and transparent expectations need to be set that offers little room for compromise.</p>
IND 2020-82	n/a	NHS Oldham CCG	<p>The indicator and timeframe are appropriate. It is necessary for a cancer patient to understand how primary care fits into care activity that is largely led by secondary care at this point. To understand what primary care can offer at this time and how to navigate the system best, is really important information. 'Within 3 months of diagnosis' is a well-suited timeframe. I would be very specific about "discussion" being a two-way process, i.e. a consultation of sorts, and not just a leaflet that is posted to the patient.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	North West Anglia Foundation Trust	<p>Support available from primary care: Within 3 months of diagnosis could be an appropriate point to contact the patient, however the timing of the appointment needs to be appropriate. If you approach the patient too soon, this may be overwhelming for the patient, but there also a risk of discussing a cancer diagnosis prior to confirmation in the acute hospital setting. The date of diagnosis may be 2-3 weeks prior to the patient being informed of their cancer and/or patients may be informed but still require staging or further tests. Is there a risk of contacting the patient for a cancer review before the patient is even aware of a positive diagnosis and cause undue stress/anxiety? This needs to be approached and managed well to ensure the patient is offered the right support at the right time. Overall, though this will lead to more positive engagement with primary care and improve the conversation/communication between patient-hospital-GP.</p> <p>Could the 3-month timeframe start from the date GP is informed 'patient aware'? All clinicians should be communicating with the GP regarding diagnosis via letter. This will account for any extended timeframe for confirming diagnosis/treatment plan, e.g. if a case needs to be discussed at SMDT or at another hospital prior to informing the patient.</p> <p>Also, how will the timeframe work for patients with a 'probable' cancer? Either those patients who are never a histologically confirmed cancer, but are clinically treated for cancer (e.g. PSA 600 in a 90-year-old patient) or those patients who are placed onto active monitoring or watchful waiting? In addition, what about those patients who present with a probable cancer, however they await surgery for confirmation? E.g. colorectal cancers. Will the 3m start from the 'probable cancer' letter or from the confirmed date of diagnosis after surgery which could be 6-8weeks+ after first presenting within the hospital.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	North West Anglia Foundation Trust	<p>Patients are now offered Holistic Needs Assessment (HNA) in either some or all cancer sites (e.g. Breast/Colorectal/Prostate). It is important that the primary care discussion is focused on what support they can offer and not necessarily signposting to support groups etc. to avoid duplication. At NWAngliaFT a patient should be offered a HNA within 6 weeks of diagnosis. If a patient completes a HNA or chooses not to this is communicated to primary care via letter. All care plans are also shared with the patient and GP for action/information.</p> <p>It is imperative that this communication is reviewed/documentated in a primary care setting to aid and support these conversations, but to avoid duplication. It will be incredibly frustrating to a patient to feel like they are discussing the same information more than once, considering just how many appointments they will be attending during the initial phase of their diagnosis.</p> <p>Primary care needs to ensure they are aware of what services are available to patients at the hospital and compliment these discussions rather than duplicate.</p>
IND 2020-82	n/a	Peninsula Cancer Alliance	<p>CAN003 misses an opportunity to promote the highest possible impact of a GP intervention around cancer care because of the timing: people with a cancer diagnosis within the last 6 months are highly likely still to be in contact with a variety of specialist support services. This might include, but not be limited to, surgical outpatient appointments, oncology outpatient appointments, ongoing chemotherapy or radiotherapy, third sector support from organisations such as Force, Macmillan and others. Bringing the indicator forward to three months compounds this issue. What is needed is a meaningful interaction between GP and patient, and both the busy patient schedule at 3 months and the administrative difficulty of offering a contact within this tight timeframe will increase the likelihood of the contact being transactional and superficial. It would be preferable for the contact to occur later, as per the proposals in IND 2020-83. By 12 months, patients are often in much less frequent contact with specialist services but may nonetheless still be dealing with significant psychological, social and physical sequelae of their cancer diagnosis and treatment. This is the timeframe in which contact should be made.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND2020-83	n/a	Peninsula Cancer Alliance	The timing of this intervention aligns much more closely with what is actually needed. CAN003 suffered because within the first 6 months of diagnosis the patient was already well supported by specialist services and indeed busy with treatment. At 12 months, as per this proposal, much of the activity around diagnosis and treatment has subsided and the patient may have a variety of psychological, social and physical problems arising from cancer diagnosis and treatment that will really benefit from a meaningful GP interaction. There are benefits in using the structured template approach, as it prompts the clinician to ask direct questions about patients' experience of treatment regarding areas that might not otherwise readily be shared (such as sexual dysfunction) but which are nonetheless important. There are also risks of a template-based approach: if the template requirements are too detailed, the clinician can get lost in completing the boxes and forget the important elements of open questioning, empathy and human contact.
IND 2020-82	n/a	Royal College of General Practitioners	For the first 3 months following a diagnosis of cancer in secondary care, the patient is often focussed on support and treatment within the secondary care environment. It can be difficult to reach patient to talk to them this early in their treatment in some cases. Can the committee consider "within 6 months" or "3-6 months"? This will enable e primary care to judge the best time to offer support the most appropriate time for contact, encouraging early contact for those with minimal secondary care treatment (e.g. skin cancer), but allow time for patients to complete the first phase of treatment when they are involved in more active treatment programmes (e.g. breast cancer)
IND 2020-82	n/a	Royal College of Paediatrics and Child Health	The date of diagnosis is crucial for cancer care review.

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	Shrewsbury and Telford Hospitals NHS Trust	<p>a) Overview and timeliness – we welcome the two new indicators as providing potentially more structured, consistent and higher impact interventions. However our experience (including feedback from CNS teams, GP’s, individual patients and support groups and data gathered by our Macmillan Living With and Beyond Cancer programme from over 220 patients and carers attending Living Well sessions in 2019) indicates that people LWBC and importantly also carers, family members and friends, differ hugely in their readiness and ability to benefit from a discussion within 3 months of diagnosis about the support available from primary care. Readiness depends on many variables including the timing and complexity of treatments across different specialties, the aim of treatment and the patient’s awareness and acceptance of the diagnosis, aims of treatment and the expected outcomes and as far as possible this information should be tailored and personalised for individual patients.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	Shrewsbury and Telford Hospitals NHS Trust	<p>b) Need for additional standardisation (to further reduce current variation and inequalities in what is delivered) Advise or provide incentives within the indicator to standardise and test locally what information about the support available from primary care is needed by people within 3 months of diagnosis and provide verbal, written and online information. Consider:</p> <ul style="list-style-type: none"> - Building on existing local resources e.g. the recently developed in house Macmillan My Passport to Living Well is being used and valued by patients in 7 specialties in Cancer Services at the Shrewsbury and Telford NHS Hospital Trust. This passport could be extended to include more information about local primary care support. Primary Care Networks could also identify the top needs for primary care support as identified in Holistic Needs Assessments being carried out soon after diagnosis in acute trusts. They could further map and respond to the needs on a network basis in collaboration with acute colleagues and the CCG's to e.g. ensure equity in addressing the top local needs. As localities differ significantly in the support available consideration could also be given to provide written and or online information about individual GP Practice areas and the larger PCN areas. - Link the indicators explicitly with existing roles and resources to optimise impact - without being prescriptive this indicator could be improved by encouraging and or incentivising links with established Care Navigator and Social Prescribing roles in primary and secondary care to consistently provide relevant primary care information at the right time for them and ensure that people LWBC are linked to services. This could proactively join up patients with services, provide a more seamless and consistent pathway for people living with and beyond cancer and ensure that this indicator is effectively delivered and makes a measurable difference.
IND 2020-82	n/a	South Yorkshire & Bassetlaw Integrated Care System Cancer Alliance Working With Derbyshire (SYBICSCAWWD)	<p>I think proactive efforts by surgeries to acknowledge a patient's cancer diagnosis and offer support is really good practice and should be encouraged and I suspect cancer patients would welcome and appreciate this even though they might be focussed on their treatment. Many practices take this as a given but more could be nudged towards this way of working with the help of incentives. I also think the timeframe is appropriate for this but I'm less sure about how easy this would be for the patient/if some may have embarked on their treatment and so a face to face might be tricky but a phone call and/or a friendly letter/leaflet would be helpful.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	n/a	The Challenging Behaviour Foundation	<p>People with severe learning disabilities may have little or no verbal communication. Therefore, family carers and those who support the individual day to day need to be included in discussions and made aware of all possible support options available from the GP and wider practice. Alternative methods of communication e.g. talking mats or Makaton may need to be used to help the individual with learning disabilities understand the options available to them.</p>
IND 2020-82	n/a	Transforming Cancer Services Team, Healthy London Partnership	<p>Yes, we agree with the three-month time period for review. However, to ensure this isn't a tick box exercise as currently reported by the primary care community, we would encourage that there is an output associated with this indicator. For example, a new care plan generated or an existing one updated, the care plan shared with the patient, details of the cancer is coded properly for proactive management/safety netting etc. In addition to care planning, we feel strongly that primary care should demonstrate they have developed plans in line with personalised care principles, such as using an holistic needs assessment to determine needs, completed a medicine review or referral to social prescribing services A quality intervention at this time would support improvements to patient experience for the support provided to patients during treatment (National Cancer Patient Experience Survey Q55. General practice staff definitely did everything they could to support patient during treatment:59% in 2018 and 58% in 2019). We would also like to ensure that the CAN001 is retained – it is imperative for proactive, long term management of people with cancer that practice registers are accurate. Comparative analysis conducted by Transforming Cancer Services Team and Public Health England showed that more than 110,000 people were missing from practice cancer registers. The analysis compared national Quality and Outcomes Framework (QOF) practice register data with the National Cancer Registration & Analysis Service (NCRAS) prevalence data between 2003 and 2017. https://www.healthylondon.org/resource/guidance-on-clinical-coding-of-cancer-patients-in-primary-care/ Accurate cancer registers at practice and network level are fundamental for supporting people re:</p> <ul style="list-style-type: none"> · Cancer and multi-morbidities, · risk of subsequent cancers, · shield themselves from diseases such as covid-19 · prevention and management consequences of cancer and its treatment

ID	Proforma question no.	Stakeholder organisation	Comment
		Question 14 : Is 3 months an appropriate timeframe to discuss with the patient the support available from primary care?	
IND 2020-82	14	Cambridge University Hospitals NHS Foundation Trust	Is 3 months an appropriate timeframe to discuss with the patient the support available from primary care? No – this does not align with the holistic needs assessment (HNA) for all pathways within the Hospital. For some cancer sites, this may be realistic, for others such as surgical pathways, this may not as a formal diagnosis and treatment plan takes longer, and so HNAs are offered later.
IND 2020-82	14	Cancer Research UK	3-month timeframe - The 3-month window is suitable for the initial offer of support, and may indeed help to address the lack of support from GPs that is often picked up in the CPES. However, this is too soon to perform a structured review. Patients might be so busy with their treatment they may well need a conversation at a later date. Having a longer time frame will offer more in the way of personalised care, so for example, the 3-month offer of support from primary care should be accompanied by a full Cancer Care Review within 12 months.
IND 2020-82	14	Coventry and Warwickshire Cancer Board	Yes, 3 months from diagnosis is a suitable time to let patients know what support they can access from primary care for their cancer diagnosis
IND 2020-82	14	East Midlands Cancer Alliance	Q14 Timeframe – 3 months looks appropriate to highlight and emphasize support to people when recently diagnosed and helps reinforce information around secondary care are having with the person and their family. This also provides an opportunity to introduce the cancer care review and maintaining contact with the person and the national quality of life questionnaire which they'll be sent 18 months post diagnosis.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	East Midlands Cancer Alliance	<p>Q14: To help primary care and most importantly the person affected by cancer to ensure a qualitative review and not a tick box this needs linking into outcomes from a holistic needs assessment undertaken (currently mostly in secondary care at points in the pathway from diagnosis to end of treatment) and linked to health and wellbeing information & support offer currently organised through secondary care</p> <p>E.g.: National health and wellbeing checklist due out, local community and voluntary support</p> <p>E.g.: Useful directory of services - https://www.cancercaremap.org/, Macmillan leaflets and websites, primary care network – social prescribers.</p>
IND 2020-82	14	East Midlands Cancer Alliance	<p>Q14. This may allow an easier transition of care and give a strong message that holistic cancer care is provided at a primary care level. The challenge will be to ensure that this discussion is communicated back to the MDT (Multi-disciplinary Team) involved in treatment.</p>
IND 2020-82	14	Highcliffe Medical Centre	<p>We feel three this is too short a timeframe as patients are seeing consultants and specialist care and may over burden patients.</p>
IND 2020-82	14	Individual 1	<p>3 months seems acceptable timeframe for the GP practice to make contact with the patient and have a conversation about the support the GP practice can provide. There would need to be a clear understanding of the definition of a 'discussion' – will it be expected to be face to face, telephone, virtual or a letter written explaining what support is available or all of these?</p>
IND 2020-82	14	Individual 3	<p>I think the 3 month timescale is difficult to achieve – when the timing for initial cancer care review moved to 3 months , it was very difficult to do a face to face review within 3 months of diagnosis as often patients are busy attending hospital appointments. If it is just a contact by telephone to advise about support available, then it may work – maybe with more detailed cancer care review by 6 months?</p>
IND 2020-82	14	Individual 5	<p>Yes, “within 3 months of a new cancer diagnosis” is an appropriate timeframe to discuss with the patient the support available from primary care. Many patients are absorbed in their hospital visits within the first several months. The breakdown of results from the annual National Cancer Patient Experience Questionnaire shows that many patients respond “my GP practice was not involved” in supporting them during cancer treatment. This is a great shame, as GP practices have much to offer a patient at this time, but it may be assumed that they are too busy with their hospital treatment and are receiving all necessary support via secondary care. Primary care should be supported in understanding what is available to their patients locally in an easily updated format so that this can be translated to the patient.</p> <p>Having this review within 3 months also sets up a channel of contact for a more robust approach to the cancer care review (at the right time).</p>

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IND 2020-82	14	Individual 10	3 months feels too tight of a timescale. Imagine someone being diagnosed and going straight for an op, they may only just be out of hospital. We always contact patients but give them time to get their heads around their diagnosis before we approach them if they do not come to us directly.
IND 2020-82	14	Individual 14	3 months for primary care review appropriate but would be helpful for a 3-month oncology treatment update from secondary care on which to anchor the consultation. This would help us answer patient's questions.
IND 2020-82	14	Individual 15	Yes, I believe this is more appropriate for sharing information about what Primary Care can do to support patients
IND 2020-82	14	Individual 16	<p>Yes. Providing an opportunity to 'catch up' with the patient after their diagnosis would be very beneficial, allowing discussions about treatment concerns, psychological issues, or other health concerns. In busy times, a new cancer diagnosis may be recorded in the patient record without any communication with the patient. Letting the patient know that we (in primary care) are aware of their diagnosis and are here to support them can be very reassuring to patients and also reminds them that primary care remains their first point of contact for other non-cancer related things. In the early stages after cancer diagnosis, management is by necessity secondary care focussed but primary care still has a vital role to play.</p> <p>However, these benefits will only be seen if the patient has a holistic, ideally face to face review. There is a risk that this could just be seen as another 'box-ticking' exercise, with the code added when a patient attends for another reason or potentially, primary care staff not involved in the patient's care, phoning the patient for a conversation 'to tick the box'.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	Macmillan Cancer Support	<p>Macmillan welcomes the proposed indicator. Primary care has a vital role to play in effectively supporting people with cancer. GPs have contact with patients at key touchpoints throughout the cancer pathway, including promoting and encouraging the uptake of screening programmes, referring patients with suspected cancer symptoms for diagnostic tests, and providing support post-treatment.</p> <p>Primary care has a significant role to play in supporting people at the time of diagnosis. The adoption of a three-month discussion provides a valuable opportunity to explore any needs the individual might have at the start of treatment and build a relationship with patients early, ensuring they know they can go to their GP for support as needed.</p> <p>The vital contribution that general practice makes to delivering personalised care is recognised in the prioritisation of personalised care as one of the national specifications to be delivered by PCNs from April 2021. Additionally, NHS England guidance around personalised stratified follow-up pathways⁶ identifies primary care involvement and joint working with secondary care as a core enabler for the pathways.</p> <p>Macmillan is aware that delays can occur in practices receiving information on cancer diagnoses, therefore the recommended three months following diagnosis timescale for the discussion to take place is right and should not be reduced. The wording should also be changed to reflect this process: 'IND 2020-82: The percentage of patients with cancer, diagnosed within the preceding 12 months, who have had a discussion within 3 months of the practice receiving confirmation of the diagnosis about the support available from primary care.'</p> <p>Macmillan has produced several toolkits, guidance documents and online training modules to support primary care teams as they connect with cancer patients from early diagnosis through to after treatment, and at end-of-life. These resources can help support GPs in maximising the opportunities provided by the three-month conversation, following diagnosis.</p> <p>⁶ NHS England, Implementing personalised stratified follow-up pathways 2020 available at https://www.england.nhs.uk/publication/implementing-personalised-stratified-follow-up-pathways/</p>
IND 2020-82	14	NHS Birmingham and Solihull CCG	Timeframe seems reasonable, but there needs to be clarity about the framework for the discussion. Otherwise this could be very variable.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	North Central London Cancer Alliance	We support this change in the indicator to facilitate early, proactive input from GPs following an individual's diagnosis of cancer. We agree that this will assist to improve patient experience and outcomes by providing opportunity for timely referral/signposting to community services closer to home. This is especially important in instances where an individual's treating hospital(s) may not be in their local area which means that the specialist team may not be aware of cancer specific or generalist support locally available? It may be challenging for some GP practices to meet the deadline of three months (especially if they receive late notification of the individual's diagnosis) for an in-depth discussion. However, the initial interaction within this time period could be an invitation email or phone call in which the offer of a discussion is made and an explanation of the rationale/content of primary care support available made clear. This will also enable the patient to have opportunity to choose the best time for them to have the discussion based on their personalised needs
IND 2020-82	14	North Central London Cancer Alliance	As per comment 1, If this interaction is framed as a practice reaching out to provide information on primary care support available - but not mandating a discussion - then 3 months is an appropriate and realistic timeframe.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	North Central London Cancer Alliance	<ul style="list-style-type: none"> · Need to clarify if CCR is to be done twice at 3 month and 12 month or would one 3month cover both? · Change wording to the “offer of”. Could the first CCR 3 month be a telephone review? · There may be some benefits for CCR at 3 months for example it would be helpful for patients to understand what support is available from primary care and for primary care to acknowledge the cancer diagnosis. This review could be conducted as a telephone appointment if appropriate for the patient. It is important to recognise that some patients will decline the offer of a CCR within the first 3m as it is the busiest time of their cancer care. · Currently there is significant variation on how the CCR at 3-6 month is conducted. There is no national standard on how the CCR should be conducted or by what format. We can measure quantity but not the quality of the CCRs. · It is important that the primary care team receive a notification of the diagnosis as soon as possible and appropriate safety netting is in place to ensure that this happens. When the primary care team receive this notification (this could be before or up to 3 months), we believe the GP should contact the patient to inform them that they are 1) aware of the diagnosis, 2) discuss the support available from the wider primary care team. · As patients will be given an HNA in secondary care (as part of the personalised care interventions at the point of diagnosis), it is important that this is shared with the patient’s primary care team. The details of the HNA could then inform the CCR and tailor to the patient’s personalised care needs.
IND 2020-82	14	Northern Cancer Alliance	<p>Yes 3 months is an appropriate time, as we move towards personalised care and Stratified follow-up, patients will need earlier support and direction from primary care to aid their journey. This discussion could be done face-to-face or remotely via video consultation. Potential limitations would be based on getting timely access to communication from secondary care colleagues and patient availability within the first 3 months as they will likely have many appointments .</p>
IND 2020-82	14	Princess Alexandra Hospital NHS Trust	<p>3 months is far more appropriate than 6 months for a discussion around support available from primary care. We often get feedback from our health and well-being events that the knowledge of the support available would be more welcome toward the beginning of their cancer journey. You could perhaps do this between 1-3 months from diagnosis for many although depending on the treatment pathway they go on to 1 month may be too soon.</p>
IND 2020-82	14	Rickleton Medical Centre	<p>We feel that the timeframe of 3 months is acceptable.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	Royal College of Paediatrics and Child Health	The reviewer believe that 3 months may be slightly too long to discuss support available from primary care and it should be done sooner than this.
IND 2020-82	14	South East London Cancer Alliance	Yes – this would allow for flexibility to account for delays in receiving information from secondary care, whilst still being within a meaningful timeframe for the patient. It would be helpful for the metric to reflect that this conversation would be most beneficial to the patient to happen as close to diagnosis as possible however within the first 3 months.
IND 2020-82	14	Surrey Heartlands CCG	I think that “within 3 months of a new cancer diagnosis” is an appropriate timeframe to discuss with the patient the support available from primary care. Many patients are absorbed in their hospital visits within the first several months. The breakdown of results from the annual National Cancer Patient Experience Questionnaire shows that many patients respond “my GP practice was not involved” in supporting them during cancer treatment. This is a great shame, as GP practices have much to offer a patient at this time, but it may be assumed that they are too busy with their hospital treatment and are receiving all necessary support via secondary care. This also sets up a channel of contact for a more robust approach to the cancer care review (at the right time).
IND 2020-82	14	SW London CCG	3 months is preferred over 6 months. In practice, earlier contact may be preferable. This then gives the opportunity to signpost the patient to appropriate services, ensure they have an exemption certificate, explain treatments/ procedures (if needed), offer support.
IND 2020-82	14	University Hospitals Birmingham NHS Foundation Trust	Absolutely agree that 3 months is a reasonable time for GP to have this discussion with their patient.

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	University of Southampton - Wessex Cancer Alliance	<p>A Health Education England funded project, Cancer Nursing Across Boundaries (CNAB), led by the Wessex Cancer Alliance is implementing and evaluating the introduction of boundary spanning cancer nurse specialists to improve integrated working across primary and secondary care for patients living with cancer. The project is being evaluated by the University of Southampton, using qualitative methods (semi-structured interviews and focus groups with GPs, practice managers, practice nurses and cancer nurse specialists). Quotes from these are in italics. The evaluation has highlighted the importance of contact from a named person from the primary care team soon after the diagnosis of cancer to identify support need swiftly and provide/signpost tailored support as appropriate.</p> <p>Practice nurse: Once [patients are] diagnosed...I will phone them as soon as I can after that diagnosis....just to introduce myself as a person they can come to...they are bombarded with information and sometimes it's a bit overwhelming but anything they are worried about they can phone and I think that people are happy to just write a name down, that's the feedback I get and then I can follow them up...They like having a named person, "don't just phone the surgery, phone me... if you want to. And would you like me to ring you in a couple of weeks to see how you're getting on".</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	University of Southampton - Wessex Cancer Alliance	<p>GP: [After diagnosis] I personally would fairly quickly follow that person up...right, let's draw breath, what's been said, what's the plan, what are secondary care planning....I give them this card – look that's my email address, that's my phone number I know you won't abuse it but email me, you can text me so that the patient can either bypass switchboard or they can send a direct communication saying can you call me...I think it's a reassuring backstop for the patient that they know that I'm there...it's just making sure that the patient knows, look I am out there, I'm there in the background, I know what's going on because I do get feedback from the hospital, I'm there if you need me but equally, you've got enough going on, don't feel the need to...you don't necessarily have to come and see me, it's OK but I am aware.</p> <p>Evaluation evidence shows that a member of the primary care team contacting patients diagnosed with cancer within three months of the diagnosis of cancer is not only appropriate: it is essential and good practice. This could be a GP or, as our evaluation has shown, in some practices, a named practice nurse being the point of contact in primary care for people diagnosed with cancer. In addition to freeing up GP time, evidence from the evaluation highlights that some nurses believe that their skillset is particularly suited to supporting patients with cancer:</p> <p>Practice nurse: I think, without being disrespectful, I think nurses could probably do a cancer review more thoroughly and better than a doctor...I think patients are more open with a nurse than a doctor. Because sometimes they'll go and see a doctor about something and then they'll come straight and see me for something else and they'll tell me something and I'll say but you've just been in to see the doctor, why didn't you speak to the doctor about that? Well, I can't really speak to the doctor about that. So, I think they're quite different and they're quite like "I don't like to bother the doctor so I came to see you"; it's that sort of attitude with a lot of people. And they think that the doctors haven't got time, whereas we've got time. And you're seeing patients repeatedly in chronic disease management so you get to know them...Sometimes just being able to see the same person and talking...just talking even if they haven't got a problem, just being able to just talk about their pathway, it just helps them just to let things out, and um just to...sometimes they just need to unburden, just get rid of it.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-82	14	University of Southampton - Wessex Cancer Alliance	<ul style="list-style-type: none"> · Yes, 3 months is an appropriate timeframe to discuss with the patient the support available from primary care. · Early engagement (peri-diagnosis) by a named practice nurse keeps links with supportive care local, accessible and in touch with healthcare professionals, often already known to patients. · Early engagement and phone access to a named nurse can prevent additional GP appointments · Early engagement builds relationships which can facilitate the later, longer term support needed after treatment ends and can include other family members
IND 2020-82	14	West Yorkshire and Harrogate Cancer Alliance	<p>The time frame suggested is appropriate. GP's most likely will be aware of the support available for patients and this should make it easier to ascertain where the patient needs to go for support. Evidence of support/ information offered / PEP and patient concerns (personalised care and support planning based on HNA) in addition to QOL information should also be available to GP's to ascertain support and signposting already offered by Secondary Care. The time frame allows for patients to be able to have further discussions with the Primary Care Team especially if further concerns have been noted by the patient once referred back to the GP. Patients may also seek to use this opportunity for reassurance and this also creates a safety net for those patients not receiving support in secondary care. The patient/ Primary care relationship will also have developed should the patient want to receive further support at a later stage. The patient has the autonomy to decline of that is what they wish to do so, however, the offer of support will have been provided.</p> <p>In addition to the above, consideration should be given to groups of people that may require additional support i.e. translation services, chaperone or those that are hard of hearing, the support for these patients can take longer to put in place, the initial period of 3 months would allow for the plans to be in place for patients.</p>
		General comments IND 2020-83 Cancer: 12 month review	
IND 2020-83	n/a	British Medical Association	<p>The percentage of patients with cancer, diagnosed within the preceding 24 months, who have a patient Cancer Care Review using a structured template within 12 months of diagnosis. We cannot support this indicator. This is chiefly a function of a cancer specialist, providing niche expertise and support depending on stage, severity, type, treatment options and patient choice.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Coventry and Warwickshire Cancer Board	I think this should be linked to when the treatment summary is done – what happens if the treatment summary is v. early – could this be combined with the cancer support available from primary care contact....is this allowed? A national template as a guide would be useful but it should not be mandated and should be localisable.
IND 2020-83	n/a	Coventry and Warwickshire Cancer Board	I would also like to suggest that the cancer care review should be offered yearly in support of the management of cancer as a long-term condition
IND 2020-83	n/a	Individual 2	I would highly support the addition of this indicator, especially with regard to the use of a structured template. As my role as a Macmillan GP facilitator, I was involved in the development of the SystemOne Cancer Care Review template and would be happy to be involved in any discussions with regard to the national template.
IND 2020-83	n/a	Individual 3	<p>I think the 12-month time frame is a good idea allowing time to personalize patient care.</p> <p>I think linking to receipt of EOT summaries is a sensible idea maybe with a caveat that if no EOT summary received, should have review by 12 months.</p> <p>I think the inclusion of a national template is useful in ensuring consistency and improving outcomes – I think there was variability in the quality of cancer care reviews in the past and this may contribute to improving quality – could it link to resources available ? Sometimes there may have been reluctance to ask questions as lack of knowledge about where to signpost when needs identified.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Individual 4	<p>Cancer Care Review: A wider window for this consultation would give greater flexibility to GP and patient to choose the best timing. Many patients are focussed on hospital treatment in the first few months after diagnosis – getting treatments sorted and maybe not yet ready to look more holistically at future support and life after treatment.</p> <p>I do believe, however, that even brief contact with primary care, early in the cancer journey, can alert the primary care clinician and make the patient feel reassured that the GP/nurse is aware and understands what is happening to them.</p> <p>It is also essential that the patient understands what to expect and when, from primary and secondary care during and after treatment.</p> <p>The arrival of an end of treatment summary is a good point to place a primary care review, so long as does not duplicate reviews in the hospital clinic and is no longer than a year from diagnosis.</p> <p>A national template would promote consistency and equity and should be designed to have efficient links to local and national resources.</p> <p>Macmillan has demonstrated that Practice Nurses can deliver high quality cancer care reviews by offering them training which builds on their existing expertise in the management of long-term illness.</p>
IND 2020-83	n/a	Individual 7	<p>Extending the cancer care review period to 12 months is very sensible as in practice it is tricky to get patients to engage with primary care in the first 6 months after treatment, but by 12 months are likely to be at end of initial treatment. Perhaps the timeframe should be extended to 18 months. The problem with linking to end of treatment summaries is that they are still inconsistently being generated, both regionally and within different cancer sites in the same hospital. Patients need most support when they are discharged from secondary care as they often feel abandoned at this point. Using a template to provide a more thorough needs assessment and consistent approach is long overdue for the CCR indicator.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Individual 8	<p>The timing of this has been debated hotly over the years. It was moved from needing to be completed within 3/12 of diagnosis to 6/12 as it was felt that the patient was too busy running around getting further investigations and operations within the first 3/12 and actually well supported by secondary care at this stage. Primary care input is more useful within the second 3/12.</p> <p>Also, I am not sure that a face to face requirement remains appropriate as most GP consultations are now remote and done by phone. It may be that video consultation is more appropriate, but that assumes that the patient has a smart phone so there needs to be some leniency in this.</p>
IND 2020-83	n/a	Individual 9	<p>This is a welcome review to the timing suggested for this review to be undertaken as it is more likely that patients will have completed / nearly completed their initial treatment 12-18 months from diagnosis</p> <p>I would support the end of treatment summaries being a trigger point for this review however I wouldn't suggest not solely relying on this as certainly based on the work we have been doing locally across Nottingham we do not have treatment summaries rolled out for all pathways yet, so would still need to link to date of diagnosis as well.</p> <p>The inclusion of the completion/use of the national template is also key to contributing to the review becoming a value-based appointment rather than a largely tick box exercise</p>
IND 2020-83	n/a	Individual 12	<p>Would it be more reasonable to do a meaningful Cancer Care Conversation after diagnosis to ensure timely support for those diagnosed with cancer as soon as possible. In my experience patients feel well supported if we call them as soon as we are notified of their cancer diagnosis – ie. within 28 hours of them knowing.</p>
IND 2020-83	n/a	Individual 12	<p>Cancer care review (after initial cancer care conversation) after 1 month – after initial diagnosis treatment may already be underway – if done within 1 month then this will prompt secondary care to send a treatment plan to the GP. If we are trying to hit the 28-day target this may be reasonable</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Individual 15	<p>“Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients?” Yes I believe 12 months would enable greater flexibility according to treatment regimens with secondary care.</p> <p>“In future, should we explore linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis?” Yes – although this would depend on treatment summaries being completed in a timely appropriate way for all patients with cancer so depends on wider system development.</p> <p>“Is the inclusion of a national template useful in ensuring consistency and improving outcomes for patients?” Yes, it is definitely a need to stipulate what should be covered in a cancer care review to allow it to be more consistent and meaningful.</p>
IND 2020-83	n/a	Macmillan Cancer Support	<p>New GP contract and personalised care</p> <p>The role that GPs play in delivering personalised care has been consistently recognised in recent national policy frameworks, including the new GP contract, which will include a specification on personalised care from April 2021. Cancer has been central to the development of this specification and the CCR will be one of the pivotal measures for delivering the personalised care specification for people with cancer.</p> <p>Macmillan welcomes the shift in the recommended timescale over which the CCR should be conducted from six to 12 months and particularly the flexible approach behind this indicator. As with any personalised care intervention, people’s needs will vary. Assuming the three-month primary care discussion (above) takes place, the 12-month timeframe provides an opportunity for GPs to tailor the review process around their patients’ individual needs at a point which is likely to be closer to their completion of acute treatment.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Merck Sharp & Dohme Limited	<p>MSD register concern that a 12-month window for the cancer care review to have taken place is potentially a long time for patients who may have complex needs. There is also a concern that due to the delayed presentation and treatment of some cancer patients due to the COVID-19 impact on cancer services, there will be patients who will need their review to have taken place much sooner than 12 months. This is particularly important when considering the mental wellbeing of some patients who may have had their treatment plans changed due to COVID or had a late diagnosis.</p> <p>MSD would endorse the suggestion of adopting the Macmillan template of the Holistic Needs Assessment.</p>
IND 2020-83	n/a	NHS Oldham CCG	<p>The 12-month timeframe is well chosen. There is some holistic assessment and care planning at secondary care level (HNA) in the earlier phases, and re-evaluation of such plans at 6-12 months post diagnosis seems appropriate. Some patients' cancer illness will progress to palliative / EOL care during this time, but our palliative care services are generally well versed in assessing and addressing holistic needs so these patients should not be missing out.</p> <p>Linking CCR timing to treatment summaries seems sensible but is only effective when treatment summaries are provided for 100% of new cancer diagnoses. Otherwise, there is a risk of some patients missing out on several aspects of the Recovery Package.</p> <p>A standard national template seems the best way forward, to reduce variation.</p> <p>Note on the proposed metrics: If we assume that Practice A is really committed to CCR and ensures that 100% of its new cancer patients get one. If it does all its CCRs between the end of month 11 post diagnosis and the end of month 12, and the denominator is the "number of patients diagnosed with cancer in the preceding 24 months", then 11 out of 24 new cancer patients would not have had a CCR yet because they are still within the first 11 months of diagnosis. This means the practice would score only 54.2% in this assessment, despite having a perfect coverage of CCRs. This needs to be factored in when deciding on achievement / payment thresholds and sliding scales.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	North West Anglia Foundation Trust	<p>12-month review</p> <p>A 12 month from date of diagnosis may be too long in some cases and too short in others. For those on a curative pathway, it might be sensible to carry out a review at the receipt of an 'Overall treatment summary', however not all hospitals or cancer sites have this implemented at present time. If this is agreed on, there needs to be effective communication to the hospitals to understand what information they send to the GP regarding end of treatment/discharge.</p> <p>For those patients not on a curative pathway, 12 months from diagnosis might be an appropriate and easier measure.</p> <p>This will be especially important for patients who are placed onto a 'self-management' or 'patient centred' pathway. Each hospital pathway is slightly different, but patients are invited for a CNS led review and to cancer wellbeing/moving on workshops for health education. This discussion would be effective as part of this pathway so patients are aware of what primary care can offer in support of self-management. It will also aid the GP practice to understand what is required for that patient in terms of follow up/reaccess to their cancer service if required.</p>
IND 2020-83	n/a	North West Anglia Foundation Trust	<p>Patients are now offered Holistic Needs Assessment (HNA) in either some or all cancer sites (e.g. Breast/Colorectal/Prostate) and a 'Patient Centred Review as part of the self-management pathway. It is important that the primary care discussion is focused to compliment and avoid duplication</p> <p>At NWAngliaFT a patient should be offered a HNA at the end of treatment, especially if they are referred to the 'Patient Centred Follow Up' (PCFU) programme. If a patient completes a HNA or chooses not to this is communicated to primary care via letter. All care plans are also shared with the patient and GP for action/information. All information regarding self-management or the PCFU programme is shared with the GP.</p> <p>It is imperative that this communication is reviewed/documentated in a primary care setting to aid and support these conversations, but to avoid duplication. It will be incredibly frustrating to a patient to feel like they are discussing the same information more than once, considering just how many appointments they will be attending during the initial phase of their diagnosis.</p> <p>The CNS will have reviewed the patient in terms of diagnosis/treatment/late effects and how to manage these/ signs+symptoms/ how to reaccess the service if required and any further referrals the patient may need relating to their cancer.</p> <p>Primary care needs to ensure they are aware of what services are available to patients at the hospital and compliment these discussions rather than duplicate.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Rickleton Medical Centre	<p>We feel a 12-month timeframe allows greater flexibility to personalise discussions of longer-term care and support.</p> <p>We feel it would be beneficial to link the timing of a cancer care review to the end of treatment summaries.</p> <p>We feel it would also be beneficial to have a national template to ensure consistency and improve outcomes for patients.</p>
IND 2020-83	n/a	Royal College of General Practitioners	<p>Use of the Macmillan template would be welcomed as a national consensus for review. This may be best timed when the patient is handed back to primary care following completion of secondary care treatment and also ensures the patients do not feel “abandoned” once discharged. This indicator would therefore be better if it related to discharge from secondary care to be of clinical relevance to patients and to ensure patients do not get lost to follow up, rather than being specifically time related to 12 months. For some cancers this will be within 1 year, for some 3 for others 5 years. It would require consistent hand over summaries from secondary care to ensure all relevant information is held within the GP record to enable appropriate conversations to be held.</p> <p>Can the committee therefore consider rephrasing the indicator to read: “The percentage of patients with cancer, discharged from secondary care (or who have had a formal hand over from secondary care) within the preceding 12 months who have has a patient cancer care review using a structured template within” or equivalent.</p>
IND 2020-83	n/a	Shrewsbury and Telford Hospitals NHS Trust	<p>a) Timing of review – we welcome the 12 month timescale replacing the current 6 month window as patients may be more receptive to and be able to benefit from a structured review in primary care when their treatment is likely to be well underway or nearing completion.</p> <p>b) Consistent use of structured template within Cancer Care Reviews (CCR’s) e.g. the Macmillan template – whilst we strongly welcome the use of this template in providing a standardised and holistic review some feedback from local GP’s in Telford (gathered via CCG wide audit of CCR’s in 2017) indicated that only 50% used a template for CCR’s and further training or the appropriate delegation of this task to trained Practice Nurses or Care Navigators may improve effectiveness. Some adverse feedback was also received about the length of the template, the time taken to complete and the evidence of positive impacts on patients. It is not clear from the indicator whether a revised version of the template is advised.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	Shrewsbury and Telford Hospitals NHS Trust	<p>c) Need for the inclusion of jointly agreed action plans evidenced as part of the CCR. The way in which the template is translated into an action plan with actions for the patient and the GP/ other members of the practice team to address needs is unfortunately not identified in the indicator. If action plans are not an integral and specified element in the proposed new reviews CCR's may continue to be viewed as "tick boxes" with no measurable impact and outcome for the patient. Increasingly in secondary care patients are being empowered to benefit from supportive self - management pathways and the increased personalisation of care and follow up. It may therefore increase consistency and continuity of care across acute and primary care and reduce inequalities if CCR's include a mandatory action plan to evidence outcomes. These action plans provide evidence of patients being enabled as far as possible to take increased responsibility for their health and wellbeing and provide tangible outcomes from CCR's for patients and GP's.</p> <p>d) Link to treatment summaries – we strongly welcome this. We believe that the link between the receipt of timely, accurate and meaningful End of Treatment Summaries and the timing of the CCR should be as explicit as possible within the proposed new indicator to ensure maximum benefit for patients and GP's. Ideally TS will inform the CCR from a patient and GP perspective and lead to a more jointly informed conversation about current and future needs as well as resulting in practical actions to ensure needs are met.</p> <p>e) Potential unintended consequence (adverse) Approximately 11% of all patients of our patients are Welsh and they and others using hospitals along the Welsh border cannot access CCR's as there is no systematic equivalent to QOF with payments to incentivise GP's in Wales. Therefore as we continue to promote CCR's to all patients (identifying the benefits of taking up invites for CCR's via our Passport to Living Well and in many of our CNS and Care Navigator interactions with patients) patients will become aware that they may not go on have a CCR. This may be disappointing and distressing to them and some may raise questions and complaints about possible variations and inequalities in provision.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	South Yorkshire & Bassetlaw Integrated Care System Cancer Alliance Working With Derbyshire (SYBICSCAWWD)	<p>I'd really welcome this. The 6 month timeframe of the CCR isn't helpful and effectively forces surgery teams to ignore their better judgement and what's in the best interests of their patients (some are likely to still be in the throes of their treatment) and instigate a discussion in a tokenistic way perhaps, rather than at the optimum time based on prompts from secondary care colleagues i.e. receipt of the HNA Care Plan and Treatment Summary and any feedback from the patient. Greater flexibility on this point would support a more meaningful conversation with the patient and give the surgery team and the patient a much better chance of achieving the goal of self-management in the longer term. Needs to be face to face ideally and not by telephone unless requested by the patient – not sure if this is apparent or even achievable now with COVID19?</p>
IND 2020-83	n/a	SW London CCG	<p>Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients?</p> <p>Having the addition of a second review is welcomed. Twelve months would be reasonable for most for discussion of longer-term aspects of care but this is variable. For example, patients with melanoma or localised breast cancer - would have finished their treatment within 3-6 months whilst others e.g. those with pancreatic cancer or advanced breast cancer are still potentially undergoing treatment. Having more flexibility around timing would be preferable. There is likely to be variation in patient need according to complexity, tumour site, and comorbidities etc.</p> <p>Primary care workload may be a barrier. However, if there is a move to a team approach to delivering CCRs this would help reduce GP workload. For example, General Practice Nurses are well placed to deliver these, provided they have access to education around cancer as a LTC, with the potential to provide more integrated care as they are likely to be managing the patients other LTCs. 'New' primary care roles such as social prescribers and clinical pharmacists may also be able to input into the CCR process where patients have complex polypharmacy or social needs for example.</p> <p>Patient focus group data from a SWL borough where an extended appointment is currently funded through a LES demonstrated the importance of patients being prepared for the CCR consultation. Many did not realise they had had a CCR and were not given any time to prepare for it. A Quality improvement could include a letter/ text to patient with a needs checklist or similar so that they could be adequately prepared for a CCR. This could be easily done via ACCuRx (or similar SMS software.)</p>

<p>IND 2020-83</p>	<p>n/a</p>	<p>SW London CCG</p>	<p>Will this QOF indicator be linked to offering a care plan (following the 12-month review)? This is something patients have told us they would find helpful.</p> <p>Barriers</p> <p>No treatment summary is a substantial barrier to an effective CCR.</p> <p>It depends how well the patient is known to the patient as to how they might feel discussing their diagnosis, how they are coping psychologically or financially. Ideally the health care professional that knows a patient best would be better suited.</p> <p>Unintended consequences</p> <p>Changing the trigger for a second CCR to the end of treatment summary being received would be dependent on all patients receiving an end of treatment summary to ensure patients were not further disadvantaged if the Trust have not provided it.</p> <p>Patients may be confused as to why GPs/primary care teams are "getting involved" when they are still under the auspices of secondary care who are the "experts" for most patients.</p> <p>It may increase demand on referrals for psychological services and use of social prescriber services.</p> <p>Equitable access to psycho-social services is important so that patients can be referred if needed.</p> <p>Will this QOF indicator be linked to offering a care plan (following the 12-month review)? This is something patients have told us they would find helpful.</p> <p>Potential for differential impact</p> <p>Older patients may struggle with video consultations and with longer discussions over the phone (under current covid constraints.)</p>
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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	SW London CCG	<p>This is not a new consideration, but we may have to tread carefully with some patients when discussing cancer and their treatment as what is reflected in hospital letters may differ from a patient's understanding. This may be the case particularly with those with dementia but equally for those having difficulty in accepting their cancer diagnosis.</p> <p>Differences in patient outcomes and patient experience for BAME communities is well documented. Thought needs to be given to how we ensure that this is considered in the invitation for CCR, the intervention and any care planning to ensure that all communities have the opportunity to engage and have meaningful consultations. Face to face and remote cancer care reviews would need to be able to take account of English as a second language. How can we use interpreters for them or signers for hearing impaired patients if online/ telephone consultations?</p> <p>In future, should we explore linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis?</p> <p>Yes, this would be welcomed. However, would be dependent on all patients receiving an end of treatment summary to ensure patients were not further disadvantaged if the Trust have not provided it.</p> <p>Is the inclusion of a national template useful in ensuring consistency and improving outcomes for patients?</p> <p>Yes, this is welcomed to ensure consistency. It has been raised that there has been an issue with the Macmillan Vision template for diagnoses coding since the move to SNOMED codes- there needs to be a robust solution for all GP clinical systems.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	SW London CCG	<p>The use of a template also ensures that non-medical aspects of care are considered – e.g. financial support etc as this can be easily forgotten otherwise.</p> <p>Patient focus group data from a SWL borough where an extended appointment is currently funded through a LES demonstrated the importance of patients being prepared for the CCR consultation. Many did not realise they had had a CCR and were not given any time to prepare for it. A Quality improvement could include a letter/ text to patient with a needs checklist or similar so that they could be adequately prepared for a CCR. This could be easily done via ACCuRx (or similar SMS software.)</p> <p>General Comment</p> <p>Will this QOF indicator be linked to offering a care plan (following the 12-month review)? This is something patients have told us they would find helpful.</p> <p>Does the cancer register remain, as it's not mentioned in the document? Having an accurate register is crucial to delivering safe and personalised care to people living with cancer. There are known gaps in the cancer register data quality – remaining a QOF requirement would increase the opportunity to improve .</p>
IND 2020-83	n/a	The Challenging Behaviour Foundation	<p>We support the more flexible time window of 12 months for reviewing personalised care. Special efforts must be made to ensure people with learning disabilities are given this review. Reviewing care must also include discussion of reasonable adjustments, recognising that the reasonable adjustments required might change over time.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	n/a	West Yorkshire and Harrogate Cancer Alliance	<p>Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients?</p> <p>This would allow further flexibility, however, the 12- month timeframe would not be ideal from diagnosis and may not suit all patients. The 12-month timeframe would be ideal after the first 3-month review as suggested above, to allow patients the time to absorb the information provided and make informed choices about their needs and care.</p> <p>In future, should we explore linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis?</p> <p>Yes, this would streamline the process especially the link between CCR and secondary care. The current process allows for patients to have health and wellbeing support in Trusts on diagnosis and is available in paper/ digital format. The information provided is from a number of sources ranging from clinicians/ CNS/Mac Millan centres and other charities. Therefore, the information that primary care/ GPs will receive on the EOTS should be once the patient has finished a particular treatment, this would seem more appropriate in terms of timing. As mentioned above at the point of diagnosis from a patients' perspective there is huge upheaval to their lives and for a possible overload of information, which means key information in terms of treatment can be overlooked.</p> <p>Is the inclusion of a national template useful in ensuring consistency and improving outcomes for patients?</p> <p>The inclusion of a national template would be helpful for consistency and would benefit patients to understand that there is a national template/ standard. This would also help to benchmark and identify good practice within localities.</p>
		<p>Question 15 : Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients?</p>	

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	Bristol-Myers Squibb	<p>(Question15) As a standardised approach the proposed 12-month timeframe could, albeit with a number of important caveats, help support an increased number of patients and healthcare professionals to better personalise discussions. The rationale for the proposed change includes evidence that the current 6-month timeframe has led to high levels of personalised care adjustment reporting. BMS is therefore supportive of changes that include the use of better informed and actionable insight to facilitate a more long-term holistic approach to follow up care. However, the following considerations should be noted:</p> <ul style="list-style-type: none"> · A mitigation plan should be in place to address any national variation in operationalising the additional proposed indicator (IND 2020-82) for patients having had a discussions within 3 month of diagnosis about the support available from primary care. Without a fully monitored approach to address any potential variation in both coverage and effectiveness of these 3 month discussions, there may be little to no patient understanding of the continuum of care that could be provided in a primary care setting at all stages of the treatment and care pathway. This should also be considered when accounting for non-primary care routes to diagnosis. · The what and the when of a cancer care review will need to continuously evolve. New and evolving standards of care are shifting the treatment paradigm to one of ever-increasing personalisation. Therefore, a standardised point in time may begin to feel arbitrary to a heterogeneous patient population. <p>Allied to the point above, the optimal timeframe to carry out a cancer care review will differ based on the type of treatment a patient is on. Treatment timelines between patients on immuno-oncology and chemotherapy vary for example.</p>
IND 2020-83	15	Cambridge University Hospitals NHS Foundation Trust	<p>Yes – in the majority of cases, but a tailored and flexible approach will be needed for some. A one size fits all approach has not been successful in implementing HNA in hospitals and instead a cancer site pathway specific approach is needed to fit with the varying diagnostic testing and pathway options for surgical, chemotherapy and radiotherapy pathways.</p>
IND 2020-83	15	Cancer Research UK	<p>12-month timeframe – we agree with this: a key element is that having one cancer type can predispose to increased risk of another (https://qcancer.org/10yr/) and this would be an opportunity to discuss personal risk and steps to mitigate risk/promote screening. The 12-month time frame also allows for recovery to a new normal and understanding different challenges to daily life/review of mental health.</p>
IND 2020-83	15	Coventry and Warwickshire Cancer Board	<p>Yes, a 12-month time frame is appropriate to personalise discussion of support for long term care</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	Coventry and Warwickshire Cancer Board	Completely. Practice nurse led CCR at this time would enable a person-centred approach relating to whatever physical, social, emotional, psychological issues related to the cancer or their treatment they are having. The timing would better support them and signpost them to other management options than the 6-month time.
IND 2020-83	15	East Midlands Cancer Alliance	Q15: Timeframe – yes this is a better timeframe to enable a more informed discussion as people are more likely to have completed their treatment in secondary care than linked to the diagnosis date and potentially be more meaningful discussion around long term management and support when someone has completed their treatment.
IND 2020-83	15	Highcliffe Medical Centre	Yes, we think this would allow a greater flexibility.
IND 2020-83	15	Individual 1	3 months seems acceptable timeframe for the GP practice to make contact with the patient and have a conversation about the support the GP practice can provide. There would need to be a clear understanding of the definition of a 'discussion' – will it be expected to be face to face, telephone, virtual or a letter written explaining what support is available or all of these?
IND 2020-83	15	Individual 5	Yes, “within 3 months of a new cancer diagnosis” is an appropriate timeframe to discuss with the patient the support available from primary care. Many patients are absorbed in their hospital visits within the first several months. The breakdown of results from the annual National Cancer Patient Experience Questionnaire shows that many patients respond “my GP practice was not involved” in supporting them during cancer treatment. This is a great shame, as GP practices have much to offer a patient at this time, but it may be assumed that they are too busy with their hospital treatment and are receiving all necessary support via secondary care. Primary care should be supported in understanding what is available to their patients locally in an easily updated format so that this can be translated to the patient. Having this review within 3 months also sets up a channel of contact for a more robust approach to the cancer care review (at the right time).
IND 2020-83	15	Individual 14	3 months for primary care review appropriate but would be helpful for a 3-month oncology treatment update from secondary care on which to anchor the consultation. This would help us answer patient’s questions.
IND 2020-83	15	Individual 16	Yes.

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	Macmillan Cancer Support	<p>Macmillan strongly supports the inclusion of this indicator on a 12-month cancer care review (CCR). The CCR is a key mechanism for primary care to deliver personalised care. The CCR needs to be a shared conversation between patient and professional, tailored to meeting the patient's needs and providing cancer information which can have a significant impact on supporting self-management.</p> <p>Ideally, all patients should be offered the opportunity to discuss their cancer diagnosis face-to-face; this is often more beneficial for both the patient and the GP. However, if this is not possible or the patient prefers not to have a face to face CCR, the CCR can be done over the telephone. Macmillan has produced a resource 'top tips on carrying out an effective cancer care review⁷' containing practical suggestions for GPs on the best way to arrange and conduct the review.</p> <p>The review should be a holistic conversation that covers clinical, practical, emotional, psychological and financial (where appropriate) aspects of the person's cancer care. As such it can provide a clear record of patients' wider needs with a view to referring to appropriate services including social prescribing and community-based services. The tool can also be used to support the wide-ranging clinical needs of people with co- or multiple morbidities, who are increasingly being supported in general practice⁸.</p> <p>⁷ Macmillan, Carrying out an effective cancer care review 2017, available at https://www.macmillan.org.uk/_images/carrying-out-an-effective-ccb_tcm9-297613.pdf</p> <p>⁸ Age and Ageing, Volume 47, Issue 3, 1 May 2018, Pages 374–380, available at https://doi.org/10.1093/ageing/afx201</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	NHS Birmingham and Solihull CCG	<p>A 12-month window does allow flexibility, and a structured template would be preferable. However, many practices will be unable to provide separate CCRs and they will need to be incorporated into LTC reviews for other conditions. Many practices have Practice Nurses trained by Macmillan to undertake the review, but many practices are not offering CCRs because they are not being paid to do them. Some CCGs have used Cancer Transformation monies to enable the CCRs to be offered. However, this is not a sustainable model. There are also concerns that many of the third sector organisations, to which patients have been signposted to in the past, will be unable to provide the support due to serious reductions in charitable funding due to Covid-19. Access to interpreting staff and leaflets in different languages is an issue in ensuring all patients have equity of access to support services and signposting.</p>

<p>IND 2020-83</p>	<p>15</p>	<p>NHS Lincolnshire CCG</p>	<p>There is a strong consensus from patients in Lincolnshire that the 6-month timeframe currently outlined in CAN003 of the QoF, is too early to conduct a CCR.</p> <p>Following consultations with over 140 Lincolnshire patients, and after engaging with Lincolnshire's cancer Co-Production group, it was identified that a timeframe of 12 months would be preferred as this permits more flexibility to attend a CCR when it is really needed. This can often be when treatment ends and care transitions out of the hospital back into Primary care. 48% of GPs we interviewed felt that 6 months was too early to offer a CCR and would prefer them to be 12 monthly.</p> <p>Benefits identified in transitioning to a 12-month timeframe for CCRs included:</p> <ul style="list-style-type: none"> - Clarity of prognosis from Secondary Care - Clear outcomes from Treatment Summary received by the practice - An opportunity to pick up on cancer recurrences - Some patients are supported well through Secondary Care (HNA) and are not requiring the CCR intervention immediately (as currently set). - Patients that want or require a CCR in the first 6 months are still able to do so. <p>[Quote from a Lincolnshire Macmillan GP] 'Should be a yearly CCR. We are framing cancer as a chronic disease and should treat it as such'.</p> <p>There are however, valid concerns from GPs and clinicians who prefer to conduct CCRs at the beginning of a patient's diagnosis and are less inclined of any change towards a 12 month timeframe. Concerns identified were:</p> <ul style="list-style-type: none"> - Some patients will enter immediately on a palliative pathway, requiring the CCR much earlier. - Some patients may need a GP referral –patient's need to know to book sooner, if needed. - This Increases the opportunity for the CCR to be opportunistic (conjoined with an unrelated appointment) - Does not suit all demographics, some patients may require support sooner i.e. those with young families, those needing time away from work and those in need of welfare support.
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<p>IND 2020-83</p>	<p>15</p>	<p>NHS Lincolnshire CCG</p>	<p>The Living With Cancer programme identifies that there is a need to be flexible within a 12 month timeframe and that the practice should work with the patient to ensure the CCR is at the correct time; taking special additional considerations for those requiring a CCR earlier and for those still in treatment beyond the 12 month timeframe.</p> <p>GPs agree that patients should be encouraged to contact their practice whenever they feel they need to discuss a cancer-related issue; irrespective of if they have had their CCR and regardless of how many months it has been since their diagnosis. What Lincolnshire would like to see is more clarity and guidance offered to GPs who are without support or structure within the current QoF indicators. Without this it will be challenging to move towards a standardised and consistent framework, resulting in patients continuing to receive dissimilarities from their CCR experience.</p> <p>Quote from Lincolnshire Macmillan GP: 'Overall it needs to be framed in a SMART or SMARTER way to really mean something'.</p> <p>Following 8 months of GP consultations the Living with Cancer Programme have been able to demonstrate how CCRs significantly vary across Lincolnshire. Examples include:</p> <ul style="list-style-type: none"> - Only 40% of practices that were interviewed confirmed that patients were told that they are attending a CCR appointment. - Less than 21% of practices interviewed routinely inform their patients of what a CCR is and how it may be of benefit, - Only 35% of practices interviewed routinely invited patients to bring a friend, family member or carer if appropriate. - Further variations include the length of CCR appointments, templates used, issues discussed, and if they appointments tend to be GP or Nurse led. <p>Using data collected from GP consultations and with support from a co-production group, Lincolnshire has developed a CCR protocol. The document offers support to practices and a clear pathway for CCR delivery. Is there a platform to work with NICE to develop a national protocol and how can Lincolnshire actively be involved in this?</p>
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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	North Central London Cancer Alliance	Yes. The CCR may be conducted over a series of appointments and involve input from different primary care professionals - GPs/Practice nurses, pharmacists, in-house physiotherapists. So this change provides flexibility for the review to be conducted at the right time for the patient by the most appropriate primary care health professional to address their needs
IND 2020-83	15	North East London Cancer Alliance	Does a 12-month timeframe allow greater flexibility to personalise discussions of longer-term care and support needs to individual patients? <ul style="list-style-type: none"> · 12-18m would give more flexibility · As many patients have ongoing issues related to their cancer or treatment, could an annual cancer review be considered (like other LTCs) · The Nuffield Trust has produced evidence showing 15 months after diagnosis these patients have 60% more A&E attendances, 97% more emergency admissions and 50% more contact with their GPs than a comparable group. · The National Cancer Patient Experience Surveys consistently show low scoring questions are related to support to patients with cancer and their families after discharge regarding the provision of information about financial support, side effects of treatment, coordinated care between hospital and community services and the opportunity for patients to discuss fears and worries. A CCR after Active treatment will enable a primary care team to continue with a supportive care plan once patients have been “discharged” from their hospital.
IND 2020-83	15	Northern Cancer Alliance	Yes, I believe it would, however it would only work if it remains aligned to the 3m discussion after diagnosis.
IND 2020-83	15	Royal College of Paediatrics and Child Health	The reviewer thinks that 1 year is too long, and that 9 months would be more appropriate, but it is not their area of expertise.
IND 2020-83	15	South East London Cancer Alliance	Yes – for many patients, they are still undergoing treatment at the current 6-month timeframe, therefore the 12-month timeframe would enable a more meaningful discussion about longer term care and support needs. However, this change is only supported in conjunction with implementation of the new 3-month discussion indicator. be most beneficial to the patient to happen as close to diagnosis as possible however within the first 3 months.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	South Yorkshire & Bassetlaw Integrated Care System Cancer Alliance Working With Derbyshire (SYBICSCAWWD)	Yes, however some guidance on what constitutes a 'good' Cancer Care Review (CCR) is useful to prevent it becoming a tick box exercise and help standardise this across the area. Some feedback from GP's was that they didn't agree with the 6/12 review, this is different for every person and needs to be based upon the individual case and clinician discretion. What we want to avoid is the phone call at the time of diagnosis from the GP being classed as a CCR, (which it has been), when actually this is just good practice. We know that CCR's are better for patients when undertaken further down the patient journey, as directed by them, usually when the flurry of secondary care input is reducing. We would favour the changes to cancer care review the current indicator dictates that a GP does a cancer care review within 6 months of a new cancer diagnosis whether that is the right time for the patient or not and does not particularly encourage the more supportive approach over an extended period.
IND 2020-83	15	Surrey Heartlands CCG	I think that a 12-month timeframe allows greater flexibility to personalise discussions of longer-term care and support needs to individual patients. Some patients are simply not ready or willing to discuss more holistic needs with their GP practice beforehand – the late effects of treatment or the “moving on” phase after treatment can be the time at which the cancer care review is most valuable. 12 months would allow for this more effectively than the current 6 month time frame.
IND 2020-83	15	Transforming Cancer Services Team, Healthy London Partnership	Yes, we agree with the 12-month time period for a subsequent review. However, to ensure this isn't a tick box exercise as currently reported by the primary care community, we would encourage that there is an output associated with this indicator. For example a new care plan generated or an existing one updated, the care plan shared with the patient, details of the cancer is coded properly for proactive management/safety netting etc. In addition to care planning, we feel strongly that primary care should demonstrate they have developed plans in line with personalised care principles, such as using a holistic needs assessment to determine needs, completed a medicine review or referral to social prescribing services It would be valuable to consider reporting at a primary care network level – some networks may wish to provide this service via one or two practices on behalf of all cancer patients within the network.
IND 2020-83	15	University Hospitals Birmingham NHS Foundation Trust	Absolutely agree that 3 months is a reasonable time for GP to have this discussion with their patient.

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	15	University of Southampton - Wessex Cancer Alliance	<p>Patients with cancer may need to have multiple appointments with different clinicians across various health settings (Rubin et al, 2015). It is important that the cancer care review in primary care is not simply another appointment that the patient has to attend adding to their treatment burden. Rather, the review should provide an opportunity for the patient to articulate what matters to them and for primary care clinicians to provide appropriate support.</p> <p>The results of our CNAB evaluation support greater flexibility in the timing of cancer care reviews as patients' needs vary along the cancer care trajectory. Our evaluation found the current Quality and Outcomes Framework (QoF) requirement for undertaking cancer care reviews within six months of the diagnosis could mean that the cancer care reviews were carried out at a time that did not provide appropriate support for the patient:</p> <p>GP: These cancer care reviews would be an excellent thing if they are done at the right time. [Often] we don't know what is going to happen because the patient has just started chemotherapy or whatever. They say "How am I going to do doctor"? We have to say, I have no idea. We've got to see how you respond and it's very early days.</p>

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IND 2020-83	15	University of Southampton - Wessex Cancer Alliance	<p>People tend not to come in once treatment has finished. They feel so happy. If they come in for something else, if you ask them about it, oh I'm all clear. That's all they're going say....That is the time that patients should come and discuss what they actually went through, and how was it and how did you cope with it, not just physically, mentally and things like that. That is the time so the cancer care review should be for a longer time and should be at a later date. Ideally after finishing treatment...Flexibility in the timing of the cancer care review...and you need that longer time to just talk about it. It shouldn't be criteria that has to be done within [x amount of time]</p> <p>The evaluation found that GP practices with locally directed enhanced services with a requirement for cancer care reviews at six and twelve months reported these provided better opportunities for personalised support for patients living with and beyond cancer: Therefore, we would suggest that a 12 month time frame for cancer care reviews in combination with contact from primary care within three months of the diagnosis of cancer would be more likely to provide appropriate opportunities to identify and address the needs of patients living with and beyond cancer.</p> <p>GP: [cancer care reviews] are probably a better place that we are in now versus two years ago when we may not have seen them [patients with cancer] again, we may not have contacted them again and there probably were cancer care reviews going on but they were just for QoF on a 12 monthly basis and now we are trying to do them 6 and 12 monthly so that's more than QoF. I think it benefits the patient, I think they feel there's continuity and I think they feel that we take more of an interest in what's going on...I think if [patients have] got that relationship with the practice where [they] feel we're involved and we know what's going on, it makes a difference.</p>
IND 2020-83	15	University of Southampton - Wessex Cancer Alliance	<ul style="list-style-type: none"> · Yes, a 12-month timeframe allows greater flexibility to personalise discussions of longer-term care and support needs to individual people. · Having an 'open' CCR document, which can be added to over a period of time was thought to be useful. Healthcare professionals felt a complete CCR rarely took place on one occasion. · Practice nurses supported to take a lead role on cancer, as they do in diabetes or asthma, increased their confidence and were able to independently undertake CCRs with patients, releasing GP appointments.

ID	Proforma question no.	Stakeholder organisation	Comment
		<p>Question 16 : In future, should we explore linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis?</p>	
IND 2020-83	16	Bristol-Myers Squibb	<p>(Question 16) An either-or approach in linking the timing of a cancer care review to the receipt of end of treatment summaries or the date of diagnosis may be unhelpful. The point of diagnosis should form both the start of a discussion between patient and professional, and the basis of a sustained patient/professional partnership to ensure the right care and support to meet the needs of the patient is built in to all stages of the treatment and care pathway. This will require ongoing engagement that might be best realised if it is de-linked from start and stop treatment points. Such an approach will also embed the importance of considering broader holistic care needs such as psycho-social support. If, however, a consensus emerges that the care review should be carried out at the receipt of end of treatment summaries, an activation process should be considered to ensure that the care review is carried out as close to the date that the patient's care is transferred back to primary care. The benefits of follow-up care, including positive outcomes such as supported-self management, are likely to be undermined if system delays and capacity challenges force further delays in a review being carried out, which is also likely to create a patient and professional perception that carrying one out is merely a tick box exercise.</p>
IND 2020-83	16	Cambridge University Hospitals NHS Foundation Trust	<p>Yes- a prompt/alert would be helpful for generation of the cancer care review. A lot of the summary information would reduce duplication as well across primary and secondary care. However, end of treatment summaries should be called 'treatment summaries' instead now to encompass all cancer patients, not just those who have a definitive end point to their treatment. This risks some patients not having access to GP support or cancer care reviews even though they may be living with cancer for many years or indeed indefinitely.</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	Cancer Research UK	End of treatment summary - We are in favour of timing the Cancer Care Review to the receipt of an end of treatment summary (instead of date of diagnosis). GPs across the Thames Valley Cancer Alliance have been incentivising high quality cancer care reviews for the past 18 months along similar links to this proposed indicator. Linking to the end of treatment would be useful acknowledging that this may be different for different patients and not necessarily at 12 months.
IND 2020-83	16	Cancer Research UK	End of treatment summary - an annual review linked to the end of treatment summary would be useful as often within the treatment summary, there are plans to arrange Echo or bone scan years after patients are discharged.
IND 2020-83	16	Cancer Research UK	End of treatment summary - however, two significant challenges linking the 'clock' to the end of treatment summary receipt rather than diagnosis date are that a) not all Trusts are actually sending out EOTS and b) there is huge variation in terms of EOT content and quality too. Patients may be missed this way and GPs penalised. There would need to be an aligned contractual requirement for acute trusts to enable this proposal to be effective across the country.
IND 2020-83	16	Cancer Research UK	End of treatment summary - The East of England Cancer Alliances has just finished running a pilot on CCRs and this is being evaluated independently by ARU. However, several things are already evident, including that it is very difficult to determine when the clock should start. If EoT summaries were sent out consistently by secondary care, it would be easier. Timing CCRs from date of diagnosis does not work: all patients are so very different, and primary care input may not be appropriate as early as 3 months, especially as during active treatment, patients receive a lot of support from CNS etc. It is when they are effectively discharged back to primary care that they need the support, and their needs - often psychological - can emerge way down the line.
IND 2020-83	16	Cancer Research UK	End of treatment summary - CCRs should be provided in Trusts following diagnosis so CCR in primary care during this time might be duplicative. However, at end of treatment care may revert more to the GP and primary care and a good understanding by the GP on the treatment that has been received, side effects, signs and symptoms of recurrence would enable the GP to have a good CCR discussion with the patient. An EOT summary for patients should also have a HNA and Care Plan too, and the GP again should have a copy of this to support the CCR discussion. We would be in favour of a national template, especially to include prevention messaging because we are aware that the quality of CCRs is variable and can happen in a very unstructured way.
IND 2020-83	16	Coventry and Warwickshire Cancer Board	Yes, in the future the cancer care review should be linked to receipt of a treatment summary, rather than date of diagnosis

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	Coventry and Warwickshire Cancer Board	In reality around 12 months is the best time but some that have had 1 treatment e.g. surgery then 6-9 months may be appropriate but for some patients that have required multiple treatment modalities, it may be beyond the 1-year mark. By linking the review to the receipt of Treatment Summary the communication between secondary and primary care could be seen as an asset of sharing of information such as patient HNAs and the review occur at a timely way.
IND 2020-83	16	East Midlands Cancer Alliance	Q16: Timing of Cancer care review with end of treatment summary- Yes however the roll out of treatment summaries remains a challenging area for secondary care. An alternative to the treatment summary is ensuring the personalised care and support plan encompasses all areas that must be included in a treatment summary – what to expect, side effects, red flags, who to contact etc and the patient consents to a copy being shared with their GP. NB: Unhelpfully COSDv9 data notes Treatment summaries as an ‘optional’ return – this needs to be mandated if it is to be driven forward
IND 2020-83	16	Highcliffe Medical Centre	Yes, I think linking it to the timing of the end of treatment sounds a good idea but I am unsure how this would fit with those who are receiving palliative treatment. Would this be only for curative treatment.
IND 2020-83	16	Individual 1	Linking to the timing of the cancer care review to the receipt of end of treatment summary rather than diagnosis would be difficult as end of treatment summaries are not fully embedded within Trusts for the main tumour sites let alone all tumour sites. Additionally, those who are treatable but not curable would not receive an end of treatment summary and therefore may end up being missed by the practice for a cancer care review.
IND 2020-83	16	Individual 5	I do not think it is a good idea to link the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis, unless high quality, detailed, timely and easily recognizable treatment summaries are being issued by all hospital cancer centres. This is not currently the case. Furthermore, although the cancer care review might be of greater value towards the end of treatment, the prompt should exist to offer this earlier on to those patients who could benefit.
IND 2020-83	16	Individual 14	I think both annual summaries and end of treatment summary from secondary care are useful rather than one or the other.
IND 2020-83	16	Individual 16	End of treatment summaries are very much ‘aspirational’ at the moment for most cancers locally. Until End of Treatment Summaries are provided for all patients, linking receipt of one to a cancer care review would potentially mean that many patients missed out on their cancer care review.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	Macmillan Cancer Support	Macmillan would welcome this approach. Currently GPs do not consistently see patients' end of treatment summaries after they are discharged from acute treatment. By linking the CCR to the End of Treatment Summary people with cancer would be more likely to have a CCR closer to the point at which their acute treatment ends and would help them benefit from a more seamless, coordinated approach. It would also require closer integration between primary and secondary care around patient handover, as identified in the guidance on Personalised Stratified Follow Up pathways. However, this requires universal adoption so that it is mandatory for every trust to issue an End of Treatment Summary for every person with cancer upon completion of their acute treatment.
IND 2020-83	16	NHS Birmingham and Solihull CCG	This seems like a sensible approach as GPs need clarity before conducting reviews and the receipt of the End of Treatment Summary can facilitate a more informed discussion with the patient.
IND 2020-83	16	NHS Lincolnshire CCG	<p>Quote from Macmillan GP: Timing for the end of Treatment Summaries rather than date of diagnosis does have its benefits as primary care often has little information, contact, or role during investigation and treatment phases.</p> <p>However, this was recorded as potentially being unachievable within the current state of practice; many factors would need to be resolved before becoming a possibility.</p> <p>Concerns from GPs, Patients and Acute Teams regarding a potential move to the end of treatment summaries:</p> <p>Treatment summaries can be delayed/ lost</p> <p>Can be sent very late and coded wrong at the practice, for example, could be coded as a hospital update, not a treatment summary – room for human error.</p> <p>Receiving treatment summaries isn't within the control of the GP.</p> <p>Some patients may need the intervention sooner i.e. palliative patients</p> <p>What if a patient requests a CCR/appointment but the practice is not in receipt of a Treatment Summary?</p>

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	NHS Lincolnshire CCG	<p>What about patients who are not scheduled for treatment? Either Palliative or watchful waiting?</p> <p>There are consistency issues from ULHT and neighbouring counties where patients are referred for treatment. Some oncology teams use a template for treatment summaries (i.e. Somerset), some use their own templates, and some send MDT notes or a formal letter. These can be from a either nurse or doctor or sometimes a medical admin team. Work is needed to standardise treatment summaries and to support hospital teams with administration processes</p> <p>There are no guidelines for when the hospital releases the treatment summary which may also be delayed for rarer cancers which require additional testing.</p> <p>May work for more established cancer pathways i.e. Breast, but not with all.</p> <p>Idea not supported by the patient co-production group; concerns were risk of delay, does not suit all cancer, and does not support those in need of immediate care.</p>
IND 2020-83	16	North Central London Cancer Alliance	<p>Yes, as it would be an excellent driver for more Treatment Summaries being conducted in the acute sector and sent to primary care and the patient. Currently there is not a Treatment Summary READ/SNOMED code which makes it difficult for a GP Practice to determine if they have received a TS for the relevant individual. Until this challenge is addressed, recommend retaining the date of diagnosis</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	North East London Cancer Alliance	<ul style="list-style-type: none"> · Many patients feel when hospital treatment ends they are “falling off a cliff” as hospital support suddenly stops so this would be a better time for primary care to step in and chance for management of long term side effects related to cancer/ cancer treatment · It makes sense to link it with treatment summaries but you would have to structure it so the denominator is the no. of treatment summaries received otherwise primary care will get penalised for the failure of 2y care to do treatment summaries. · Not all cancer will have an “end date” for e.g. blood cancers are never discharged and so finding right time for each cancer may vary. · Should not depend on treatment summary from hospital as currently inconsistent. Although useful to have and guiding the conversation. There is often a lag between patient hospital care finishing and a treatment summary being completed and sent to GP and therefore could be a missed opportunity for support during that crucial time. <p>A Treatment Summary could act as a trigger for Primary Care to invite patient in for a CCR after active treatment. Example trigger points for a CCR could be: a) at notification from hospital confirming a new diagnosis (via 2ww, routine outpatient, screening, A&E, other primary care routes, previous diagnosis/recurrence). B) newly registered patients with cancer diagnosis in last 5 years. C) on receipt of Treatment Summary and /or transfer of care / discharge to community or primary care teams.</p>
IND 2020-83	16	Northern Cancer Alliance	With upcoming push towards personalized care and stratified follow up, the treatment summary will be a critical piece of communication, enabling primary care colleagues to make personalized recommendations to each patient. The first new indicator should be linked to diagnosis, but I feel the Cancer Care Review (at 12 months) would be better linked to the treatment summary.
IND 2020-83	16	PC24 Social Enterprise	Yes – pragmatic and factors in different cancers and treatments.
IND 2020-83	16	South East London Cancer Alliance	Yes – this would provide context on which to base the CCR on and help guide the conversation about the treatment the patient has undergone, concerns regarding prognosis, and advice and onward referral for ongoing consequences of treatment. It would also take account of the variation in length of treatment for different tumour types. However, this would be dependent on End of Treatment Summaries being completely embedded in secondary care, which is still a work in progress.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	South Yorkshire & Bassetlaw Integrated Care System Cancer Alliance Working With Derbyshire (SYBICSCAWWD)	This would be useful once all areas have access to these in a timely manner across all tumour groups this is still a while away. The time scales for treatment options will be very different for different people, if any are available at all. The best case scenario would be that the CCR could build upon the Holistic Needs Assessment (HNA)/treatment summaries and be a transferable, electronic document across primary/secondary care, as we know a lot of the same questions will be covered in both.
IND 2020-83	16	Surrey Heartlands CCG	I do not think it is a good idea to link the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis, unless high quality, detailed, timely and easily recognizable treatment summaries are being issued by all hospital cancer centres. This is not currently the case. Furthermore, although the cancer care review might be of greater value towards the end of treatment, the prompt should exist to offer this earlier on to those patients who could benefit.
IND 2020-83	16	Transforming Cancer Services Team, Healthy London Partnership	Yes, we agree in principle that cancer care reviews should be timed with the end of primary treatment – this is the time when our patient partners inform us that they feel most vulnerable. However, for this to work, secondary care must be able to share practical and relevant treatment summaries in a timely manner for primary care teams. To date, uptake in London remains well below 10% and we have been trying to implement this for more than six years. When treatment summaries are produced, they are not always shared with primary care, they can be very lengthy, not tailored for a primary care audience, and not clear on what information should be coded by primary care for safety netting. Digital compatibility can also prevent efficient and safe transfer of information between primary and secondary care professionals. If this change is made to QOF measures, then guidance would need to consider <ul style="list-style-type: none"> · what constitutes a Treatment Summary – i.e. it is not a discharge letter. A clear definition and quality standards of a treatment summary is needed (e.g. use a national template). · What is expected of primary care if a Treatment Summary is not received from the secondary care team.
IND 2020-83	16	University Hospitals Birmingham NHS Foundation Trust	Yes, I agree this is a very sensible opportunity to identify patients at end of treatment. Perhaps a Code needs to be lined to EOT summaries in order to flag an appointment?

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	16	University of Southampton - Wessex Cancer Alliance	As recommended above, flexibility in the timing of cancer care reviews is important. Consideration should be given to linking the timing of cancer reviews to the receipt of end of treatment summaries rather than date of diagnosis as evidence demonstrates that patients with cancer may feel abandoned after the end of active treatment which normally takes place in secondary care (Olsson et al, 2008). Therefore, primary care clinicians may have a particularly vital role in identifying and addressing patients' ongoing support needs at the end of cancer treatment. It is, however, important that the primary care team have been involved in offering support to the patient from diagnosis as patients may lose contact with their primary care team during treatment: GP: I think there is that bit which is so secondary care driven, as in chemotherapy, radiotherapy, they're going through...that people often disappear into that secondary care bubble. And for me it's just making sure that the patient knows, look I am out there, I'm there in the background, I know what's going on because I do get feedback from the hospital, I'm there if you need me but equally, you've got enough going on, don't feel the need to...you don't necessarily have to come and see me, it's OK but I am aware. Just making sure that they know that I am there. But it's also when those treatment cycles come to an end, it's let get together again, draw breath, where are we now?
IND 2020-83	16	University of Southampton - Wessex Cancer Alliance	<ul style="list-style-type: none"> · Yes, linking the timing of a cancer care review to the receipt of end of treatment summaries rather than date of diagnosis should be explored. · Many people are still receiving treatment at nine months or recently completed and are not able or wish to attend GP for a CCR. · CCR at time of treatment summary enables better personalised long-term planning of physical health and supportive care. <p>Not all people are receiving treatment summaries from the cancer teams.</p>
		Question 17 : Is the inclusion of a national template useful in ensuring consistency and improving outcomes for patients?	

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	17	Bristol-Myers Squibb	(Question 17) Macmillan Cancer Support's recovery package includes a useful template for supporting the development of a national cancer review framework. This should be further built on to ensure a diverse range of patients can review how effective/appropriate it is to the diverse and varied needs of the UK cancer population. Healthcare professionals should also be provided with appropriate training to ensure that their approach to carrying out a review is inclusive and responsive to the needs of the patients they support.
IND 2020-83	17	Cambridge University Hospitals NHS Foundation Trust	Yes - similar to the co-produced templates for the treatment summaries would be useful. In addition, a standard alert system for GPs to be able to quickly and seamlessly generate cancer care reviews, utilising systems and templates already used to capture patient information would also help with an equitable approach to care. As patients take treatment summaries with them (should they move home, attend university etc), a national framework for a template would ensure consistency of approach for both the summary and a cancer care review.
IND 2020-83	17	Coventry and Warwickshire Cancer Board	A National template like that produced by Macmillan is very useful for standardising care, providing consistency and improving patient outcomes
IND 2020-83	17	Coventry and Warwickshire Cancer Board	Yes, standardising the content of a CCR is helpful. The use of a template is positive for practice nurses if they are the best placed to be doing these reviews.
IND 2020-83	17	East Midlands Cancer Alliance	Yes, to ensure a qualitative cancer care review rather than a tick box exercise. There are good examples already in use such as the Macmillan template which helps prompt the clinician to carry out a more holistic, patient-centred cancer care review, and makes reference to holistic needs assessment, treatment summary, care planning and health and wellbeing information and support. One of our clinical leads, Dr Heetan Patel, helped develop the SystemOne Macmillan Cancer Care Review template and has volunteered directly with you to provide his assistance with the development of a national template.
IND 2020-83	17	East Midlands Cancer Alliance	Q17. Recommend there should also be reference to people receiving a national quality of life questionnaire which launches Sept 2020 and will be sent to them 18 months post their diagnosis.
IND 2020-83	17	Highcliffe Medical Centre	Yes, it provides a consistent approach nationally.

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ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	17	Individual 1	<p>A national template would be useful to be used as an aid memoire for those undertaking the cancer care review of the topics that could be covered, but there is a risk a template would continue the view that a CCR is a tick box exercise.</p> <p>However, as we want to push the personalised care agenda not all topics would be suitable for all patients, so a letter to patients to explain what could be covered prior to the cancer care review would help patients be prepared and focus the conversation on the most important aspects. Could there be an opportunity to link the CCRs to the Holistic Needs Assessments and Care Plans that are meant to be rolled out within the Trusts.</p>
IND 2020-83	17	Individual 5	<p>The inclusion of a national template would be incredibly useful in ensuring consistency and improving outcomes for patients. This will allow for experienced nurses to help provide more cancer care reviews and embed the notion of cancer as a long-term condition. There are standardised templates for other long-term conditions in widespread use.</p> <p>If employed, the template should not be burdensome or off-putting in terms of length and non-essential codes. Something along the lines of the current Macmillan EMIS Cancer Care Review template.</p> <p>The “useful links” section of this template however is inadequate – it needs to be kept up to date and linked to current social prescribing and other local/national cancer support services.</p>
IND 2020-83	17	Individual 14	<p>I think a best practice national cancer review template is helpful to ensure consistent quality of care for all patients. The Macmillan cancer care review is well established and therefore tried and tested.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	17	Individual 16	<p>I am delighted that cancer care reviews are the subject of consultations and I am convinced of the benefits of a structured CCR template. We have been enthusiastically promoting the use of the Macmillan CCR template in our locality but unfortunately, there has not been widespread uptake. The main barrier to uptake has been the amount of time required to do a holistic CCR; I estimate a comprehensive review is likely to take at least 15-20 minutes and this doesn't really fit with the 10-minute consultation. Few GPs are likely to be able to accommodate 'double appointments' for a CCR, due to ever increasing workload and staffing issues. With some additional cancer training, practice nurses are ideally suited to carry out CCRs, being experts in holistic reviews of other long-term conditions. However, staffing issues within nursing teams have prevented this happening locally. The other concern is whether the primary care team have the skills and knowledge to deal with social/financial/employment issues and if not, are they able to signpost to relevant organisations? An ideal model might include a 2-part CCR with a clinician completing the 'medical' part of a CCR and social prescriber or other similar professional covering the other equally important aspects of the CCR.</p>

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IND 2020-83	17	Macmillan Cancer Support	<p>Macmillan strongly supports the adoption of a national template for the CCR. There is a pre-existing template available to all GPs nationally and it is consistent between systems.</p> <p>This national standardised CCR template has already been developed by Macmillan and integrated into EMIS Web, TPP SystemOne and INPS Vision.</p> <p>The template encompasses a holistic approach and have been widely welcomed by the primary care community as a framework to guide conversations. Use of the Macmillan CCR template has encouraged patients to be more open about discussing their needs and in doing so, play an active role in shaping the delivery of their care. The CCR provides an opportunity for a personalised care conversation that is led by the patient and focuses on what matters to them.</p> <p>The CCR also provides an opportunity for improved integrated working with emerging PCN roles such as social prescribers, who can support patients to navigate to and/or access further support or information as needed. A standardised CCR template is essential to guide this conversation and open up holistic avenues that may otherwise not be considered such as finance, psychological support and physical activity as demonstrated by the findings below. Macmillan has developed a training offer for social prescribers on supporting people with cancer and a guide for PCNs9 to enable them to utilise the potential of these new roles in cancer care.</p> <p>The CCR template has also been recognised to increase and improve standardised coding for consistency and enhance the ability for data capture via the searches. The template has integrated links which can signpost to additional help during the conversation itself to support with any needs or concerns that arise via information sheets embedded into the template.</p>

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IND 2020-83	17	Macmillan Cancer Support	<p>Use of the template also facilitates a more comprehensive review. Macmillan's 2019 pre-post primary care toolkit (which contains the CCR template) practice survey identifies that after using the toolkit the proportion of reviews covering:</p> <ul style="list-style-type: none"> · Cancer information leaflets and resources increased from 37.89% to 97.22% · Benefits of physical exercise or signposting to resources increased from 37.89 to 85.71 · Information about the financial impact of cancer increased from 27.78 to 80.56 <p>The impact of the templates is reflected in successive evaluations showing that:</p> <ul style="list-style-type: none"> · 71% of patients reported being 'very satisfied' with the process¹⁰. · the number of GPs who reported using the Macmillan CCR Template after completing the toolkit containing the CCR increased from 11.3% to 65.7%. · the quality of the reviews increased and include several key elements. For example, the proportion of reviews addressing the psychological impact of diagnosis increased from 58.33% to 97.22% after using the template. · 97% of GPs practices felt better equipped to support people as they go through treatment and are recovering from cancer (87% to a moderate or large extent). · Benefits cited by GPs included that it enabled a higher quality CCR and it has made the cancer review more holistic, more structured and allows better identification of the patients' main problems and needs"¹¹. <p>9 Social Prescribing for cancer patients: a guide for Primary Care Networks, 2019 available at https://www.macmillan.org.uk/_images/social-prescribing-network-guide_tcm9-355360.pdf</p> <p>10 Macmillan Cancer Support, Evaluation of Macmillan's Cancer Care Review Template, available in PDF.</p> <p>11 Macmillan, Pilot Outcomes related to Cancer Care Reviews 2020 (attachment submitted with this consultation response)</p>
IND 2020-83	17	NHS Birmingham and Solihull CCG	<p>A national template is useful, but there needs to be a national agreement and discussion about funding CCRs as many areas are reliant on Transformation Funding, which is an unsustainable model. I'm not sure about the quality of reviews under the current QOF arrangements, which may largely be a tick box exercise and there may be insufficient time dedicated to a proper review for the patient.</p>

ID	Proforma question no.	Stakeholder organisation	Comment
IND 2020-83	17	NHS Lincolnshire CCG	<p>Patients and members of the Lincolnshire Co-Production group recognise that a national template could be an important toolkit for CCRs becoming more standardised reducing geographical variations that are currently evident.</p> <p>[Patient quote] It's important to know I am receiving the same care as everyone else, regardless of what cancer I have or where I live.</p> <p>A national template could provide GPs with clearer guidelines as to key areas that the CCR should investigate as a minimum (medication review, symptoms, lifestyle etc.). This would allow for information to be recorded, measured, and audited, whilst potentially being easier to explain to patient during their appointment.</p> <p>A national template may also support the conversation of Practice Nurses being more involved with CCR delivery and the long-term care of patients. A template would offer guidance and support as well as offering structure to appointments that are Nurse Led. Following Lincolnshire Cancer Update Workshops in 2019, Practice Nurses identified that a comprehensive template would be of significant value for structuring their appointments.</p> <p>The Living with Cancer programme acknowledges that many GPs prefer not to use a template for CCRs. A 2018 pilot study evaluating the Macmillan CCR template reported that GPs felt the template had too many questions and took the appointment away from being a holistic and patient led conversation. In some instances, GPs have developed their own templates (i.e. on Ardens) to suit their own individual consultation style. For these practices, guidance is needed from QoF on the minimal data sets that should be routinely collected.</p> <p>Lincolnshire's Living With Cancer programme believes there is no 'one size fits all' with cancer care. We would like to escalate to NICE that any template developed would need to consider rarer cancers, various demographics, and to expand on key concerns that the patient may experience beyond medications, treatment and symptom management.</p>

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IND 2020-83	17	NHS Lincolnshire CCG	<p>Are CCR appointments patient focused and personalised if they are conducted following a predetermined set of [potentially] generic questions?</p> <p>Quote from Macmillan GP: can be seen as a balancing act; too much and they become a tick box, too little and they are pointless/offer little support.</p> <p>GP Quote: Often national templates are less suited to general practice because they are designed by people outside of working general practice.</p> <p>Quote from Macmillan GP: 'The danger with a national (or even local) template is the inevitable inclusion of what can be measured rather than what matters. Free text is always more useful.</p> <p>It is conceivable that a national template could prompt a more holistic conversation with the patient, which covers a variety of key issues and helps identify a broader range of concerns that the patient may have. However, it is unclear if this will lead to improving outcomes for the patient which may rely more on developing systems which support practices when referring to offers of support in the community, including Neighbourhood Teams, Social Prescribing etc. GPs may be hesitant to ask questions if they do not have the skillset or knowledge to support – such as fatigue management and exercise.</p>

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IND 2020-83	17	NHS Lincolnshire CCG	<p>The Living with Cancer programme recognises the importance of patient education and that much work is needed to inform patients at the earliest and most appropriate opportunity of what a CCR is. Patients who are informed will more likely attend appointments with a clearer insight into what matters to them, empowering patients to identify how they would like to receive support from their practice. This focuses the CCR to become more patient led and enables their GPs to immediately address the needs of the patient whilst maximising their appointment time together. The Lincolnshire Living with Cancer programme would like to work with NICE to introduce a national letter template that GPs and practices can send to their patients within the first 3 months of diagnosis. The benefits would include:</p> <ul style="list-style-type: none"> - Clearly identifying to the patient what a CCR is and why it is offered to the patient (reduce unnecessary anxiety) - Clearly outlines the role of their GP and the this is the start of an ongoing conversation - Patient is informed of the timeframe for the CCR and a prompt that patients can book their CCR sooner, if required. - Informs the patient to consider 2 or 3 main issues they wish to discuss, which will help the GP in their time together and could help triage the patient to the most appropriate person in the practice (i.e. the Practice Care Coordinator or Practice Nurse for signposting/referrals) - Informs the patient to bring a family member, carer or friend if needed - Directs the patient to immediate support such as Macmillan resources, Cancer Research UK and potentially adapted to include local information, including Support groups and community-based programmes. <p>The Lincolnshire Living with Cancer programme is able to share a letter template developed with a patient co-production group.</p>
IND 2020-83	17	North Central London Cancer Alliance	<p>Yes. The NCL Cancer Alliance has been advocating for more standardisation of the cancer care reviews and ensuring the baseline standard of care provision is of high quality. The Macmillan template is a high quality one which is available on EMIS - we would support in rolling out.</p>

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IND 2020-83	17	North East London Cancer Alliance	<ul style="list-style-type: none"> · National template is useful to guide conversation. Worry that it can become a tick box exercise for some practices and so auditing quality would ensure meaningful conversation. Would improve patient outcomes. Should allow for different health care workers e.g. social prescribers to complete the CCR · National template useful in benchmarking the expected standard of a CCR, especially if it links to resources. · A National template should allow the primary care team to conduct a CCR in a mode most appropriate for the patient i.e. telephone consultation or a face to face and be standardised to reduce inequity around the support from primary care. · Studies have shown clear evidence that patients and carers would welcome a structured cancer care review and feel it legitimises raising their concerns about their cancer and the consequences of any treatment (Kendall, Boyd et al, 2006; Kendall, Mason et al, 2015) · There have been a number of projects across the UK where further guidance for the CCR has been proposed and in some cases incentivised. A report by the Transforming Cancer Services Team reviewed and compared these projects and the best practice from all taken forward into the creation of the following proposed 4 Point model.
IND 2020-83	17	North West Anglia Foundation Trust	<p>A nationally agreed template/framework for the review would be helpful to measure quality, but also for communication with the hospital. If we are able to understand what primary care of offering in their discussions post treatment, we can ensure we are not duplicating or cross-communicating to the patient.</p> <p>As part of integrated pathways, it is important that both primary/secondary care understand and appreciate what support they offer the patient in a bid to not overwhelm or duplicate the system. A template will also ensure equality between patients. They should receive the same basic elements of information/support, with additional personalised support. This ensures no patient is treated unfairly.</p>
IND 2020-83	17	Northern Cancer Alliance	Imposing national templates may not be appropriate. I think allowing Regional Cancer Alliances to have autonomy in developing templates would be better and more focused on the needs of local populations. The present cancer care review templates (most of which are designed using guidance from MacMillan) allow sufficient autonomy with a good structure form which to follow.
IND 2020-83	17	PC24 Social Enterprise	Yes

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IND 2020-83	17	Royal College of Paediatrics and Child Health	Pertaining to question 17: there are good and bad points, it would have consistency between, but this would make the service more tick box like instead on concentrating on patient care. A guideline for this would be more useful, but it is not their area of expertise.
IND 2020-83	17	South East London Cancer Alliance	Yes, however there is already a national template developed by Macmillan, which has been designed to integrate with the 3 main GP IT systems, with links to relevant patient information. Therefore, the metric should be reworded to 'using the current Macmillan National Template. Local measures would still be required to support education and training on quality cancer care reviews.
IND 2020-83	17	South Yorkshire & Bassetlaw Integrated Care System Cancer Alliance Working With Derbyshire (SYBICSCAWWD)	Definitely, that needs to be transferable between all GP systems having a 'basic' template with the ability to make it more localised to the area would be really useful and makes CCR a lot easier for clinicians if they know where to signpost people to. It is also felt that Practice Nurses can be invaluable in undertaking these, either stand alone or along with other chronic disease reviews, as they are sometimes (but not always) better at asking the right questions.
IND 2020-83	17	Surrey Heartlands CCG	I certainly think that the inclusion of a national template useful in ensuring consistency and improving outcomes for patients. This will allow for experienced nurses to help provide more cancer care reviews and embed the notion of cancer as a long-term condition. There are standardised templates for other long-term conditions in widespread use. If employed, the template should not be burdensome or off-putting in terms of length and non-essential codes. Something along the lines of the current Macmillan EMIS Cancer Care Review template. The "useful links" section of this template however is inadequate – it needs to be kept up to date and linked to current social prescribing and other local/national cancer support services

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IND 2020-83	17	Transforming Cancer Services Team, Healthy London	<p>Yes, we agree in principle that a structured, national template should be used. This is to ensure that a structured conversation takes place that is truly holistic and allows for discussion on needs related to physical, psychological, social, spiritual concerns. This could be delivered by a GP, practice nurse or other registered healthcare professional within the network. It must be aligned to the national expectations for the NHS regarding personalised care and support planning (from NHS England's comprehensive model of personalised care). This in turn will support improvements to quality of life, as will be measured through the national quality of life metric via NHS England's national cancer programme. This metric will be rolled out from September 2020.</p> <p>It would also support improvements to patient experience of health and social care during and after treatment (National Cancer Patient Experience Survey Q52-56).</p> <p>The 12-month review should naturally lead into long term condition management as part of the future DES specification on personalized care for those with complex needs. Cancer must be explicitly categorized as a long-term condition for those who survive beyond the first year of diagnosis and regular reviews should be provided by primary care professionals. This is supported by the Transforming Cancer Services Team's "case for change" published in 2015.</p>
IND 2020-83	17	University Hospitals Birmingham NHS Foundation Trust	<p>Yes, it is good to know that each cancer patient will be offered the same support. A national template will ensure parity and equity for all and act as an aide memoire for GP's to be asking all the relevant questions to ensure personalised care.</p>
IND 2020-83	17	University of Southampton - Wessex Cancer Alliance	<p>Evidence from the evaluation demonstrates that primary care clinicians would welcome an evidence-based structure with which to approach cancer care reviews.</p> <p>GP: If [the cancer care review] actually reminded you to say, ok, have I started to really think about...is this the right time to be thinking about choice of place where you want to die, you might say absolutely not...they're just going through their chemotherapy. That's the last thing they want to be talking about, they're talking about living not dying. So if the cancer care review was something that was a prompt to say right, have I really started to think about this dozen bullet pointed questions that I need to think about... so that we are not missing the obvious things that, frankly, can be missed which are things like, actually, where would you like to die, what are your thoughts about the future.</p>

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IND 2020-83	17	University of Southampton - Wessex Cancer Alliance	<p>In a number of practices involved in our evaluation, primary care clinicians followed a template developed by the cancer care lead GP in the Thames Valley Cancer Alliance. Clinicians welcomed the template as it provided a structure with which to approach the cancer care review and an evidence-based checklist to ensure that busy generalist clinicians were able to consider patients' needs holistically.</p> <p>GP: Cancer care reviews are useful because we follow the cancer care review template developed by the cancer care PCN GP lead. We follow all these things, social prescribing, exercises, family, and treatment. In the QoF, all it says is cancer care review, you just say yes, yes, cancer care review done. It doesn't really mean anything. Whereas the template gives full detail. So we decided to fill this in for all cancer care reviews because we have to do a cancer care review within six months so we fill that template in....</p> <p>Therefore, evidence from the evaluation suggests the inclusion of a national template would be useful to ensure consistency, improve outcomes for patients and provide an evidence-based structure for busy clinicians.</p> <p>Complete results from the Health Education England funded CNAB project should be available in early 2021 via the Health Education England and Wessex Cancer Alliance websites.</p> <p>References: Rubin, G et al (2015) The expanding role of primary care in cancer control The Lancet Oncology, 16 (12): 1231 – 1272. Olsson, U et al (2008) Patients' experiences of the recovery period 3 months after gastrointestinal cancer surgery. European Journal of Cancer Care, 11: 51-60.</p>
IND 2020-83	17	University of Southampton - Wessex Cancer Alliance	<p>Additional supporting clinical experiences from the Cancer Nursing Across Boundaries project: Yes, the inclusion of a national template would be useful to ensure consistency and improve outcomes for patients.</p> <ul style="list-style-type: none"> · National template needs to capture more social concerns e.g. caring responsibilities not just that they have been given an info leaflet or a DS1500 form completed. · Important that the same national template is compatible with ALL primary care systems e.g. Ardens or Emis · Important to capture journal entries, not just boxes ticked. · Ideally, share CCR between practice nurses and cancer nurse specialists to promote team approach to care as well as patients.

