

Freedom of Information Request – Patient Reported Outcome Measures in Cancer Care at UHBW

This Freedom of Information request asks about the use of patient reported outcome measures (PROMs) in oncology. PROMs are questionnaires which measure a patient's own view of their health, i.e. they are completed by patients about themselves. PROMs may be used to measure symptoms, quality of life, wellbeing, health status etc. Patient reported experience measures (PREMs) and other service evaluation questionnaires, such as the National Cancer Patient Experience Survey (CPES) or the Family and Friends Test (FFT) are not in the scope of this request.

1. Name of trust or hospital:

University Hospitals Bristol and Weston NHS Foundation Trust

2. Are PROMs used routinely (rather than as part of a trial or research study) in cancer clinical care? YES

This FOI request is asking about PROMS in use in 'oncology', but it also asks about PROMs used routinely in 'clinical cancer care'. 'Cancer Care' is much broader than just oncology, it also includes cancer diagnostics, surgery and many other supportive cancer services eg. palliative care, rehabilitation etc.

For the purposes of this FOI, feedback has been collated from cancer services across the whole Trust (all cancer services), not just from oncology.

Many people with cancer are recruited into active studies and research trials in cancer services at UHBW, which incorporate relevant PROMs as part of their evaluation, but as specified in the FOI, they have not been included.

3. If yes, please fill in the table below using one row per oncology clinic/patient group e.g. palliative care, breast cancer, chemotherapy clinic. Please add more rows if necessary.

Oncology clinic/patient group	Which PROMs are used?	How are PROMs completed – electronically, paper, both?	If electronically, what platform, app or system is used to collect the data?	Are oncology PROM results integrated with electronic health records? (YES/NO)	For what purpose are oncology PROMs collected: symptom monitoring, follow up, signposting to support services, other (please specify)?
All cancer patients – offered at the point of diagnosis and at the end of treatment.	Macmillan Holistic Needs Assessments (HNA)	Both	Electronically using the Macmillan 'My Care Plan' portal and a paper option is also available.	No	Identification of all holistic needs Assessment of wellbeing Symptom monitoring Signposting to support services

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All UHBW cancer patients, (identified through national cancer dataset) – postal invitation at 18 months post diagnosis	NHS England, National cancer QOL questionnaire – using EQ-5D and EORTC QLQ-C30	Both	www.cancerQoL.england.nhs.uk	No	Quality of life wellbeing and late effect symptom monitoring
All cancer patients referred to psychology	PHQ9, GAD7, FACT-G	Paper	N/A	No	Measure of change in depression, anxiety and QoL
Prehabilitation* - prior to cancer surgery	Eq5D-5L and DASl	Both	Careflow EPR (entered by the clinician on the screen in clinic)	Yes	Assess change in health related quality of life start and end of intervention Risk stratification for exercise intervention
Prehabilitation* – prior to cancer surgery	Plan to start EORTC QLQ-C30	Both	DrDoctor	Yes	Assess change in QoL, wellbeing and symptom monitoring
All teenagers and young people accessing cancer Aftercare services	I AM	Electronically	I AM app	No	Wellbeing and symptom monitoring Signposting to support services Follow-up
All paediatric cancer patients - within 3 months of ending treatment and then offered again at 6 months	End of treatment HNA/ CNS assessment tool	Electronic – Careflow EPR clinical note Paper copy to family/GP/Shared care professionals.	Careflow EPR	Yes	Wellbeing and symptom monitoring Signposting to support services Follow-up

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Craniopharyngioma / midbrain patients – trialling a pre-clinic assessment tool.	Wellbeing clinic tool / HNA	Electronic – Careflow clinic note Paper copy to family/GP/Shared care professionals.	Careflow EPR	Yes	Wellbeing and symptom monitoring Signposting to support services Follow-up
Joint Child Brain Injury clinic	CBITrust HNA	Paper (they have their own data collection process and parents' consent for their information to be held by the charity. The CBIT professional offers a verbal handover of their assessment.	Held by CBIT	Held by CBIT	Wellbeing and symptom monitoring Signposting to support services Follow-up
Paediatric BMT patients	BMT HNA	Paper copy held in medical notes electronically on local BMT shared drive	Shared drive	No	Wellbeing and symptom monitoring Signposting to support services Follow-up
All paediatric cancer patients, when planning return to school	Return to school health care plan needs assessment	Paper & saved to Evolve	NA	Yes	Wellbeing and symptom monitoring Signposting to support services Follow-up

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All Head and Neck cancer patients, prior to each follow-up appointment	There are no validated H&N cancer PROMs. We use Washington University Quality of Life Survey.	Electronically but patients can request paper questionnaires	Microsoft Forms	Manually at discretion of clinician/patient.	symptom monitoring service improvement signposting to support services
Head and Neck cancer patients with dysphagia, requiring intensive swallow therapy	SWAL-QOL MDADI: MD Anderson Dysphagia Inventory	Paper	NA	No	Monitoring impact of symptoms on function and quality of life. Pre- and post- therapy outcome measures.
Colorectal cancer patients in surveillance	'Health MOT' questionnaire developed for My Medical Record	Both, if they are able to access the My Medical Record system they are able to do it online. If not, they are able to complete a paper version.	My Medical Record	No, they remain on My Medical Record but are not stored on the patient EPR. NB. If concerns are raised by the patient in the questionnaire, the concerns and subsequent actions taken by the clinical team are noted in the EPR.	As part of supported self-management, the questionnaire is used to highlight concerns that can then be discussed and investigated further.
Germ cell cancer patients in surveillance	'Health MOT' questionnaire developed for My Medical Record	Both, if they are able to access the My Medical Record system they are able to do it online. If not, they are able to complete a paper version.	My Medical Record	No, they remain on My Medical Record but are not stored on the patient EPR. NB. If concerns are raised by the patient in the questionnaire, the concerns and subsequent actions taken by the clinical team are noted in the EPR.	As part of supported self-management, the questionnaire is used to highlight concerns that can then be discussed and investigated further.

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Ovarian cancer patients in surveillance	'Health MOT' questionnaire developed for My Medical Record	If they are able to access the My Medical Record system they are able to do it online.	My Medical Record	No, they remain on My Medical Record but are not stored on the patient EPR. NB. If concerns are raised by the patient in the questionnaire, the concerns and subsequent actions taken by the clinical team are noted in the EPR.	As part of supported self-management, the questionnaire is used to highlight concerns that can then be discussed and investigated further.
Myeloproliferative Neoplasm	MPN 10	both	via MPN Voice app	No, written in clinic letter	symptom monitoring
All patients referred to Radiotherapy Late Effects service	EORTC QLQ- C30 PAM measure 13 EQ 5D-5L Macmillan HNA	Both	HNA - Electronically using the Macmillan 'My Care Plan' portal and a paper option is also available.	No	Wellbeing and symptom monitoring Signposting to support services Follow-up

* Prehabilitation - support and advice to maximise physical and nutritional health and wellbeing prior-cancer surgery (with the intention to extend to pre-oncology treatment when resourced). Prehabilitation is evidenced to improve outcomes.