

DNA Nucleotide Excision Repair Disorders Service (All Ages) (Service) 2020/21

Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
1648-19-101a	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Timeliness of support		Proportion of patients with a newly confirmed diagnosis of XP being offered support within 10 working days of referral	The number of XP patients who are offered support within 10 working days of referral	Number of patients with a newly confirmed diagnosis of XP during reporting period .	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-102	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Equipment		Proportion of XP patients with UV filter films fitted to home, work, school and car windows	Number of XP patients with UV filter films fitted to home, work, school and car windows	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-103	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome			Proportion of XP patients using visors, gloves, hats, eye cover when outside	Number of XP patients using visors, gloves, hats, eye cover when outside	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-104a	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	UV meter		Proportion of patients living in a UV-safe home environment as defined by a safe reading on the UV meter .	Number of patients who are found to be living in a UV safe home environment	Total number of patients whose home environment was assessed during the reporting period	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-105	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Sunburn		Mean annual number of sunburn episodes reported for XP patients	Mean annual number of sunburn episodes reported for XP patients	N/A	Annual	Annual	Provider Submitted	N/A		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-106	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Skin cancer staging		Proportion of skin cancers with complete staging information for XP patients	Number of skin cancers with complete staging information for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-107	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Eye cancer staging		Proportion of eye cancers with complete staging for XP patients	Number of eye cancers with complete staging for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-108	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Skin cancer stage 1		Proportion of skin cancers with stage 1 cancer for XP patients	Number of skin cancers with stage 1 cancer for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-109	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Skin cancer stage 2		Proportion of skin cancers with stage 2 cancer for XP patients	Number of skin cancers with stage 2 cancer for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-110	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Skin cancer stage 3		Proportion of skin cancers with stage 3 cancer for XP patients	Number of skin cancers with stage 3 cancer for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21

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															Q1	Q2	Q3	Q4
1648-19-111	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Eye cancer stage 1		Proportion of eye cancers with stage 1 cancer for XP patients	Number of eye cancers with stage 1 cancer for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-112	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Eye cancer stage 2		Proportion of eye cancers with stage 2 cancer for XP patients	Number of eye cancers with stage 2 cancer for XP patients	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-113	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process	Eye cancer stage 3		Proportion of XP patients with stage 3 eye cancer	Number of XP patients with stage 3 eye cancer	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Lower is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-114	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical outcome	Clinical trial		Proportion of patient caseload involved in a clinical trial	Number of XP patients on caseload involved in a clinical trial	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-115	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process			Proportion of CS/TTD patients who have Vit D levels measured	Number of patients who have Vitamin D levels measured	Number of XP patients on caseload	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21
1648-19-116	Domain 2: Enhancing quality of life for people with long-term conditions	Clinical process			Proportion of CS/TTD patients with confirmed diagnosis referred to service to be offered support including home-visiting and a bespoke care passport	Number of patients eligible offered home-visiting and a bespoke care passport	Number of patients with confirmed diagnosis of CS/TTD during reporting period.	Annual	Annual	Provider Submitted	Provider Submitted		Higher is better		N/A	N/A	N/A	Apr 20 - Mar 21

Data collection has been approved by the Review of Central Returns - ROCR
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