

Supplemental Data Table 1. Comparison of surveillance intervals among the three VHL patient groups

	Recommended time interval (median, months)	Annual follow-up at the VHL clinic (median, months)	Follow-up loss at the VHL clinic (median, months)	Non-participants of the VHL clinic (median, months)	<i>P</i>
Ophthalmic examination	12	12 (2–40)	12 (3–36)	12 (3–38)	
Imaging of the CNS (CT or MRI)	12	12 (6–24)	16.5 (13–18)	13 (1–48)	0.362
Imaging of the abdomen (CT/MRI or US)	12	12 (6–20)	12 (2–18)	12 (3–48)	
Examination for catecholamine levels (24-hr urine or plasma)	12	12 (8–18)	12 (6–17)	13 (6–38)	
Audiometry	12	15 (12–48)	24 (18–48)	20 (12–48)	0.146
Total	12	12 (2–48)	13 (2–48)	12 (1–48)	

Abbreviations: CNS, central nervous system; CT, computed tomography; MRI, magnetic resonance imaging; US, ultrasonography; VHL, von Hippel–Lindau.