

Supplementary Table 5. Public health actions required for symptomatic patients with an unclear diagnosis

Tissue involved in procedure	Action for instruments is determined by the number of cycles of use and decontamination they have already been through since used on the index patient				Patients exposed to instruments
	Action for Surgical instruments by number of uses to date		Action for flexible endoscopes by number of uses to date		
High infectivity (brain or spinal cord, cranial nerves or ganglia, posterior eye, pituitary glands)	Fewer than 20 uses Remove from general use quarantine pending diagnosis	More than 20 uses Reprocess & return to use	Fewer than 20 uses Remove from general use quarantine pending diagnosis	More than 20 uses Remove from general use quarantine pending diagnosis	No patients should be traced and notified until the diagnosis is clear
Medium infectivity (spinal ganglia; olfactory epithelium; if variant CJD is still being considered: tonsil, appendix, spleen; thymus, adrenal gland; lymph nodes & gut-associated lymphoid tissues)	Fewer than 10 uses Remove from general use quarantine pending diagnosis	More than 10 uses Reprocess & return to use	Fewer than 10 uses Remove from general use quarantine pending diagnosis	More than 10 uses Remove from general use quarantine pending diagnosis	No patients should be traced and notified until the diagnosis is clear
Low infectivity (all other tissues not listed above)	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	Reprocess & return to use	No patients should be traced and notified

Symptomatic patients with an unclear diagnosis 1) diagnosis is unclear but not variant CJD 2) diagnosis is unclear but variant CJD is still being considered. A greater range of medium risk tissues should be considered during the risk assessment if variant CJD has not been ruled out as a potential diagnosis. Irreversible actions such as permanent disposal of instruments and notification of subsequently exposed patients should not be conducted until the diagnostic status is clear.

Before an instrument is quarantined it should be first decontaminated to the required standard (see 2021 CJD guidance manual).
CJD; Creutzfeldt-Jakob disease.