Developing Local Guidelines for Neurology follow up versus discharge

There is variation in practice between consultants as to which patients they organise to follow up. This variation reflects the nature of the patients' problems, the treatments they are on, the organisation of local services, preferences of both the patient and the doctor. Which patients need to be followed up will change with time as new ways for patients to access services are developed (for example patient initiated follow ups), new treatments are made available or through links with alternative services, for example community services, palliative care or geriatrics.

It is recommend that consultants working together in a unit actively consider how to provide the most effective service for their patients. Below is the output of such a discussion held in 2017 in one neuroscience region. This is presented as an exemplar to prompt local discussion rather than a definitive proposal.

This discussion should also consider how patients might be referred back into the service if not on regular timed follow up, for example patient-initiated follow up via phone line or email with specialist nurse.

Southampton Guideline for neurology follow up vs discharge 2017
These are general principles only and decision to FU or discharge must be tailored to individual patients

As a general principle:

- Patients with chronic neurological disease will be followed up if they are on disease modifying therapy or have unstable disease that requires active monitoring and/or treatment changes.
- We aim to discharge most patients with neurology symptoms after their first appointment, even if investigations are outstanding. If the investigations show something that requires FU this can be reinstated.

Discharge	Follow up
Headache *Most patients with primary headache disorders / analgesic associated headache after 1st appointment* *IIH in remission (e.g. stable for 6-12 months, depending on various factors)*	*IIH while still on medication or unstable* *Patients receiving Botox* *Cluster HA and other less common headache syndromes may be seen more than once.*
M.S., CIS and other neuroinflammatory *Low risk CIS (normal scan)* *Progressive or stable MS not on DMT if can be followed up by specialist nurse / community MDT (some variability here)*	*All MS on DMTs* *RRMS not on DMTs but may require DMT (clinical or scan monitoring)* *High risk CIS (abnormal scan)* *Other neuroinflammatory diseases on DMT (e.g. sarcoid)*
Movement Disorders	*Most PD seen at least every 12 months.*

Some PD may be discharged to elderly care (e.g. frail elderly) or to a skilled specialist community team (e.g. in Dorset) *Essential tremor (any atypical features may see once more)* *Dystonia not receiving botox* *Tics* *Most RLS*	*Patients receiving Botox or on tetrabenazine* *Most other progressive neurodegenerative movement disorders i.e. HD, PSP, MSA*
Peripheral nerve *Axonal length dependant peripheral neuropathy, including idiopathic, alcoholic and diabetic* *Genetic neuropathy once diagnosis made and fully explained* *GBS after 1st review post admission* *Mononeuropathies, radiculopathies and brachial neuritis once diagnosis established (1-2 appts)*	*CIDP, MMN or any others on immunosuppressive treatment* *Other atypical neuropathy may be seen until diagnosis and pattern established (e.g. rapidly progressive, possible amyloid etc.)*
Neuromuscular and muscular *MG once off treatment and in remission* *IBM*	*MG on treatment* *MND* *Myositis on immunosuppression (unless can be transferred to rheum)* *Genetic myopathies where monitoring required e.g. Myotonic Dystrophy*
Epilepsy *1st seizure* *> 1 year seizure free* *> 2 years post successful resective surgery* *> 1 year refractory epilepsy but stable and no changes planned*	*All other epilepsy until in remission or optimally treated* *Women of childbearing age on Valproate (or other high pregnancy risk regimes)*
Functional including NEAD *Most especially those main diagnosis is chronic fatigue syndrome(note: we do not accept referrals for*	*Somewhere providing education and value*

CFS to our service unless other diagnoses require exclusion)	*Until diagnosis confirmed or if organic disorder e.g. epilepsy coexists*
Cognitive including NPH and concussion *Stable MCI* *Most > 65 dementia – refer to memory clinic* *Concussion / stable post brain injury cognitive impairment – may need neurorehab* *NPH*	*Atypical (e.g. FTD) and young onset dementia - spec clinic* *Autoimmune encephalitis while on immunosuppression or unstable*
Genetic disorders *NF – refer to regional coordinators* *Most once diagnosed, information and support given*	*FU if require specific monitoring* *Rare disorders and patients with unknown mutation may be FU in spec clinic*
Vascular *Most TIA /stroke does not need FU (stroke nurse FU once after discharge or TIA clinic)* *Cervical artery dissection after 1 appointment and FU imaging (usually rescan at 3-6 months before withdrawal of antiplatelets)*	*Cerebral vasculitis on immunosuppression, (systemic vasculitis including GCA can be discharged to Rheum)* *Some unusual progressive disorders e.g. moya moya (spec clinic)*