Figure 2

Generic pathway for any patient in a state of prolonged disorder of consciousness (unaware or minimally aware)

Weeks 0–4:
- Identify and contact relatives, friends
- Establish best interests process for decisions
  - Is there a deputy?
  - Is there an advance decision?
- Contact specialist neurological rehabilitation service
  - Level of consciousness/awareness
  - Preventative care

Week 4:
- Assessment by specialist neurological rehabilitation team:
  - Neurological status (cause, and any additional factors)
  - Prognosis
  - Patient needs (care, therapy/prevention, equipment)
  - Family needs (practical, emotional, information)
- Hold full best interests meeting to consider management of:
  - Immediate threats to life (e.g. cardiac arrest)
  - Less immediate situations (e.g. deterioration, need for ITU)
  - Limits of care in general
- Consider:
  - Move to specialist rehabilitation centre (preferred option)
  - Move to other specialist care setting (e.g. nursing home)
  - Timing of next best interests meeting
  - How specialist rehabilitation input continues
- Register the patient on
  - Local register for local follow-up etc
  - National register (to be set up)

Weeks 4–26 (or 52) (i.e. until no more change likely if unaware):
- Planned regular assessment of awareness, usually using the Wessex Head Injury Matrix (WHIM)
- High level care to maintain wellbeing
- Close involvement of family
  - Support, making observations on responsiveness
- Best interests meetings if needed
  - especially if unexpected decision needed
- Usually in specialist neurological rehabilitation centre

See Specialist Neurological Rehabilitation input in right-hand column

Specialist Neurological Rehabilitation input (inpatient/outreach):
- Assessment to establish
  - Cause, and complicating factors
  - Level of responsiveness
  - Intervention needs
- Goal setting to set realistic goals for
  - Improvement and level of function
  - Length of stay and next placement
  - Organising funding, care, placement
- Intervention
  - Care, documenting ongoing care needs
  - Equipment, providing or recommending needed equipment
  - Family support
- Discharge
  - After formal best interests meeting
  - To appropriate setting able to meet care needs
- Including monitoring responsiveness
  - With planned follow-up arrangements by specialist service

When state stable:
- If unaware
  - Six months if metabolic cause (hypoxaemic or hypoglycaemic)
  - Twelve months otherwise
- If minimally conscious
  - Three to five years

Formal process of:
- Full assessment of
  - Neurological status, and drugs
  - Level of awareness
  - Establishing and documenting prognosis
  - Documenting needs
- Best interests meeting to consider specifically
  - Withdrawal of clinically assisted nutrition and hydration
    - Always, if in vegetative state
    - Sometimes, if in minimally conscious state
  - Response to any deterioration (acute or otherwise)
  - Ongoing care and follow-up/monitoring

Long term (or when patient improves):
- Provide specialist rehabilitation for anyone regaining full awareness
- Always establish means of contact and review
  - Outline circumstances when this should be initiated
  - Give method for making contact (who and how)
- Ensure that care team can and does monitor responsiveness
  - Using WHIM or similar
  - At agreed frequency (e.g. 3 sets of observations, every 3 months)
  - Sending results to specialist service