

North Cumbria University Hospitals   
NHS Trust

Cumbria Partnership   
NHS Foundation Trust

  
*Cumbria*

**PROTOCOL for  
Supporting People with  
Learning Disabilities to  
Access Acute Services**

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## SUMMARY

This Protocol supports People with Learning Disabilities to Access Acute Hospital healthcare when attending hospital for diagnostic investigations or treatment, or emergency admission. This includes equality of access to services, easy to understand information, best interest decision making, and understanding of the role of the Community Learning Disability Teams or supporting staff or carers.

Changes to the original document are:

- Reference to Mental Capacity Act, p11, website address.
- Section 8.3, p16, Dental and Maxillo-facial surgery, contact numbers.
- References, p22, additional references to Mental Capacity Act, and Hospital Communication Book.
- Patients Attending Theatre and Recovery p 26, amended content.
- Reference to 'Medication Needs Sheet', p30.
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## 1. INTRODUCTION

This protocol was initially developed by a multidisciplinary group representing Kingston Hospital, the learning disability service in Kingston Primary Care Trust and the Royal Borough of Kingston. It has been adapted by representatives from:

- North Cumbria University Hospitals NHS Trust.
- NHS Cumbria.
- Cumbria Partnership Foundation NHS Trust.
- The Glenmore Trust.
- Family representatives after consultation with service users.

It addresses a number of important issues for people with learning disabilities when using the acute health services within North Cumbria University Hospitals Trust. This includes equality of access, easy to understand information, best interest decision making and the role of the Community Learning Disability Teams and support staff.

## 2. OBJECTIVE

The main objective of this protocol is to ensure that people with learning disabilities are able to access high quality health care when attending North Cumbria University Hospitals Trust for diagnostic investigations or treatment.

### 2.1 Further objectives are:

- To enable staff at the acute Trust to develop a better understanding of people with learning disabilities and to equip them to deal more effectively with the particular needs of each individual
- To clarify for residential and other Learning Disabilities staff attending hospital with a person with learning disabilities their supporting/caring role and the boundaries between their caring role and the nursing role of the professional hospital staff.
- To support Learning Disabilities staff attending the Acute Hospitals with clients
- To implement successfully the use of the Patient Passport for people with learning disabilities using hospital services
- To provide an opportunity for hospital and learning disability staff to work together to develop
  - Effective communication
  - Training
  - Raising of awareness
  - Easy to understand information for service users.

### 3. SCOPE OF PROTOCOL

This protocol applies to all staff employed within North Cumbria University Hospitals Trust who have responsibility for the care of patients, or provide a service, including those with learning disabilities.

### 4. PROTOCOL

The following information provides a background for the rationale of producing this protocol.

The White Paper *Valuing People: a new strategy for learning disability for the 21<sup>st</sup> Century* was published in 2001. Chapter 6 of *Valuing People* focuses on the importance of improving the health of people with learning disabilities. The Department of Health's objective is "to enable people with learning disabilities to have access to health services designed around their individual needs with fast and convenient care delivered to a consistently high standard and with additional support where necessary".

In 2003 the Valuing People Support Team issued *All Means All*, reinforcing the entitlement of people with learning disabilities to access high quality mainstream health services. Also in 2003, the action guide *Valuing Health for All (Primary Care Trusts and the Health of People with Learning Disabilities)* was published. *Valuing Health for All* focuses on the action that Primary Care Trusts (PCTs) should take with their partners to reduce health inequalities for people with learning disabilities.

The National Patient Safety Agency (NPSA) published *Understanding the patient safety issues for people with learning disabilities* in 2004. The NPSA identifies five patient safety priorities including:

- the vulnerability of people with learning disabilities in general hospital
- the lack of accessible information
- illness or disease being mis- or un-diagnosed
- dysphagia
- the use of physical interventions

All priorities have potential relevance for people with learning disabilities attending hospital.

An investigation conducted by the Disability Rights Commission entitled *Equal Treatment: Closing the Gap* has identified a number of issues associated with diagnostic overshadowing and the perceived negative or discriminatory attitudes of health care staff. The report was published in September 2006 and is available on the internet at: [www.rcpsych.ac.uk/member/disabilityrightscommissioni.aspx](http://www.rcpsych.ac.uk/member/disabilityrightscommissioni.aspx)

This policy applies to staff within the North Cumbria University Hospitals Trust providing health services and caring for people with learning disabilities. The term “Learning Disability (LD)” is used to describe a person who has developmental delay or intellectual disabilities which are usually evident from birth or early childhood.

There are three core criteria which must be met for the term learning disability to apply:

- Significant impairment of intellectual function.
- Significant impairment of adaptive and or social function (ability to cope on a day to day basis with the demands of his/her environment and the expectations of age and culture).
- Age of onset before adulthood.

Learning disability does not include:

- The development of intellectual, social or adaptive impairments after the age of 18.
- Brain injury acquired after the age of 18.
- Complex medical conditions that affect intellectual and social /adaptive functioning: e.g. dementias, Huntington’s Chorea.
- Specific learning difficulties: e.g. dyslexia, literacy or numeracy problems, or delayed speech and language development.

The term “Learning Difficulties”, which is often used in educational services to describe people with specific learning problems, does not indicate that a person has a learning disability as defined above.

Community Learning Disability Teams provide specialist support for adults with an assessed learning disability as described above who are eligible to receive services.

People with learning disabilities may present as having:

- difficulties communicating and expressing needs and choices
- difficulty understanding their diagnosis, treatment options or services available to them
- difficulty understanding the consequences their decisions can have on their health status
- difficulties in adapting to a hospital environment and the expectations of hospital staff.

The main aim of this policy is to ensure that people with learning disabilities are able to access high quality health care when attending North Cumbria University Hospitals Trust for diagnostic investigations or treatment.

Following a workshop held in early 2005 involving staff working in Kingston Hospital, specialist learning disability health staff and managers of some residential services care pathways were developed and a range of key priorities identified. It is these key priorities that North Cumbria University Hospitals Trust will follow as the principles of optimum care.



The key priorities were as follows:

- Involvement of the community learning disability team
- Providing information that is easy to understand for hospital staff
- Providing easy to understand information for service users with learning disabilities about their hospital stay
- Support for people with learning disabilities whilst in hospital
- Best interest decision making.

## 5. COMMUNICATION

Many barriers to healthcare can be overcome by effective communication. Health staff will need to communicate effectively not only with the person with a learning disability but with paid carers, family members, advocates, care managers and learning disability team staff.

Many people with learning disabilities have difficulties with communication. This may include problems with expression, articulation, comprehension, and coping with social situations. People with learning disabilities have difficulties understanding complex sentences and abstract concepts with time being a particularly difficult concept to comprehend. This should be considered when discussing appointments or future treatments. It can be helpful to relate appointments to concrete events in the person's life. They may also have difficulty understanding written communication and this should be taken into consideration when providing patient information such as information about appointments, particularly if pre-appointment instructions are included.

Many are unable to communicate verbally and rely on other methods such as gesture, pointing or facial expression to communicate their needs. Problems with communication are often linked to difficult or challenging behaviour which can then present a barrier to accessing appropriate health care.

An individual's capacity to understand and communicate can be affected by a number of factors, including anxiety, pain and distress, unfamiliar people and environments. People with learning disabilities may also be unable to describe adequately their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell.

There are a number of strategies which can assist in ensuring more effective communication when meeting a person with learning disabilities for the first time. These are attached as **Appendix 6**, but may also include aids such as the 'Hospital Communication Book' available in hospital wards (see References).

It is essential that there are clear communication channels identified between the hospital and specialist learning disability services and contact information for the relevant teams and hospital departments should be made readily available. A contact sheet is attached at **Appendix 10**.

There is a range of easy to understand information available to enable people with learning disabilities to better understand hospital appointments and admissions. The community learning disability teams can advise on the resources available.

## 5.1 Patient Passport

The Patient Passport will assist in ensuring that relevant information about a person's health status and support needs can be made available to hospital staff.

The Patient Passport (**Appendix 8**) is a document which provides clear and concise information in an easy to understand format regarding the person's health and support needs. The Patient Passport belongs to the service user and should accompany the person for all hospital appointments and admissions. The person with learning disabilities and the main carer will have access to "How to complete the Patient Passport" information booklet. This will assist them in accurately completing The Patient Passport so important medical and contact information is given to healthcare staff. It is reviewed and updated regularly to provide a record of the individual's health management.

## 6. CONSENT AND BEST INTEREST DECISION MAKING

### 6.1 Mental Capacity Act 2005. (MCA)

The Mental Capacity Act 2005 provides a statutory framework to empower and protect people who may lack capacity to make some decisions for themselves, e.g. people with learning disabilities, dementia, mental health problems, stroke or head injury.

The MCA applies to all people who work in health and social care involved in the treatment, care or support of people over the age of 16 who are unable to make all or some decisions for themselves.

The MCA is accompanied by a statutory Code of Practice which provides guidance on how it will work on a day to day basis. Anyone working in a professional or paid role with people who lack capacity will have a legal duty to have regard to the Code of Practice. It can be found at:

[www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm)

The Act is underpinned by five key principles:

- **A presumption of capacity** – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
- **Individuals being supported to make their own decisions** - a person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- **Unwise decisions** – just because an individual makes what might be seen as an unwise decision, he/she should not be treated as lacking capacity to make that decision.

- **Best Interests** – an act done or decision made under the MCA for, or on behalf of, a person who lacks capacity must be done in their best interests.
- **Least restrictive option** – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The North Cumbria University Hospitals NHS Trust Mental Capacity Act Policy can be found at <http://nww.staffweb.cumbria-nhs.uk/acute/policies/mca.pdf>

## 6.2 Capacity to Consent to Medical Treatment:

The Mental Capacity Act describes the following two stage test to determine capacity:

- (i) Is there an impairment of, or disturbance in the functioning of the person's mind or brain? If so,
- (ii) is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?

A person is considered able to make a decision if he/she is able to:

- a) understand the information relevant to the decision
- b) retain that information
- c) use or weigh that information as part of the process of making the decision, or
- d) communicate his/her decision (whether by talking, using sign language or any other means).

Consent can only be said to be valid if it is voluntary, the person knows what they are consenting to, and has a real option of saying yes or no.

Please refer to the document '*Making Decisions – Helping people who have difficulty deciding for themselves - A Guide for Healthcare Professionals*' for more information on assessment of capacity. It can be found at:

[www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm)

Healthcare professionals must assume that the person has capacity to make decisions. The emphasis is on staff establishing the reasons why they consider that the person lacks the capacity to make each particular decision at the time it has to be made. This must be based on reasonable belief.

Health professionals must make every effort to help and support the person to maximise their potential to make their own decisions or, at least, to participate as fully as possible. Staff must consider how much information to convey to the person and how to make the most of the abilities that the person has. This may include choosing the best time and location for the assessment, allowing the person sufficient time to become familiar with the issues and communicating in simple language or through the use of pictures and photos.

## 6.3 Particular Needs of People with Learning Disability in relation to decision making

People with learning disabilities may have particular difficulties in relation to decision making for some of the following reasons:

- Difficulty understanding relevant information, which is linked to the person's verbal and general cognitive skills (e.g difficulties with attention, distractibility ) and the methods used to convey information.
- Difficulty retaining relevant information.
- Difficulty appreciating the personal significance of information.
- Difficulty with reasoning and use of information to arrive at a decision (e.g concreteness, difficulties with abstracting and generalising).
- Lack of experience of decision making.
- Tendency to acquiescence and suggestibility, and difficulties being assertive.
- Emotional factors such as fear, anxiety.
- Difficulties in expressing choices.

Some of these difficulties relate to the person's learning disability in that their cognitive function is limited in some areas. Others reflect the person's social and psychological experience (e.g. relative powerlessness) and represent "secondary handicaps".

Support should be provided to maximise the person's ability to participate as fully as possible in decisions about their own life.

#### **6.4 Medical Treatment**

Doctors proposing treatment for a patient have a personal responsibility to judge whether that person has capacity to give consent and a duty to explain the treatment, benefits, risks and any alternatives.

The doctor has ultimate responsibility for ensuring that an explanation has been provided to the patient and that their consent has been obtained, involving other members of the clinical team as appropriate.

#### **6.5 Determining Best Interests:**

Everything that is done for or on behalf of a person who lacks capacity must be in that person's best interests. The Act provides a checklist of factors that decision-makers must work through in deciding what is in a person's best interests. A person can put his/her wishes and feelings into a written statement if they so wish, which must be considered by the decision maker. Also, carers and family members have a right to be consulted. See North Cumbria University Hospitals NHS Trust, Mental Capacity Act Policy.

#### **6.6 Consent to Treatment:**

**No one** – spouses, partners, relatives, carers or advocates – can legally give or withhold consent to medical treatment on behalf of another adult and should never be asked to sign a consent form on behalf of another person. Relatives and carers should be consulted about the patient's best interests though only where this is commensurate with the duty of confidentiality and the patient's wishes.

Be aware that family members may have a different view and perspective of the patient's wishes and views to that of paid carers, therefore it is important to consult all those closely involved with that person and consider all views. The person, though, has a right to confidentiality and may not wish certain people to be involved in the decision making process.

## **6.7 Resolution of Disputes (Escalation Process):**

If there is significant disagreement regarding the treatment of a patient who may lack capacity, the courts have identified certain circumstances when healthcare professionals or others must make an application to the High Court. These are:

- Where there is serious uncertainty about the patient's capacity to consent, or their best interests; or
- Where there is serious unresolved disagreement between a patient's family and health professionals.

If consensus cannot be reached, or if someone wishes to challenge a judgement, there are a number of options that could be explored, including:

- Involving an advocate who is independent of all the parties involved in the decision to act on behalf of the person lacking capacity (Independent Mental Capacity Advocate)
- Getting a second opinion (for medical treatment)
- Holding a formal or informal case conference
- Attempting mediation – though reaching consensus will not necessarily determine best interests of the person lacking capacity.

If there is disagreement between learning disability staff and the hospital team about the proposed treatment or non-treatment of a person with a learning disability, the concerns should be raised initially with the ward manager and the consultant responsible for the patient. Learning disability service staff should also raise their concerns with their line manager. Concerns should be communicated to the community learning disabilities team nurses or team leader, who will inform the Associate Director for Learning Disabilities Services in the Cumbria Partnership NHS Foundation Trust.

Hospital staff should escalate their concerns through the relevant Matron and Consultant.

## **7. COMPLAINTS**

Service users and/or carers should be supported to use the hospital's complaints procedure if there are concerns that cannot be addressed by ward or clinic staff. The Patient Advice and Liaison Service (PALS) can assist with addressing concerns and issues on behalf of service users and carers. An easy to read leaflet has been produced providing information on how to comment or complain. Should there be a complaint the service user/carer should contact PALS.

PALS can be contacted through the hospital switchboard:

- Cumberland Infirmary – 01228 814008

- West Cumberland Hospital – 01946 523818

## **8. PREPARATION FOR HOSPITAL VISITS/ADMISSIONS/DISCHARGE**

Many people with learning disabilities are very anxious about medical treatment and hospital environments and this anxiety can sometimes be expressed in behaviour which can be challenging for staff to manage. Prior to any planned hospital appointment or admission, learning disability staff with support from the community learning disability team, will ensure that the person is offered the individual support required to facilitate the visit. This may on occasion include the use of sedation to manage anxiety but only under the guidance of a medical practitioner.

Learning disability staff will ensure that all relevant information, including the patient passport, details of medication or any specialist advice or guidelines, is made available to hospital staff. (See **Appendix 1**, Core principles)

### **8.1 Out Patient Appointments**

(See Appendix 2, Outpatient Attendance)

The Lead Nurse of the Out Patient Department can be contacted prior to appointment if specialist equipment and/or services are required. The service user and/or his/her carer can give his/her Patient Passport to his/her named/clinic nurse on arrival and prior to consultation.

The named/ clinic nurse will assist during the consultation and will be available post consultation to provide extra information and direct the service user and his/her carer to other hospital departments as required.

If transport is required for the next appointment this can be arranged by the clinic nurse (subject to clinical need).

Follow up appointments should be avoided unless clinically essential, in cases where the service user presents with distress, extreme anxiety or challenging behaviour in hospital settings. If a follow up appointment is not offered, care arrangements should be discussed and negotiated with the community learning disability nurse who can liaise as necessary with the GP.

Learning Disability staff will ensure that they liaise with the Lead Nurse or Consultant and/or identified contact, as appropriate, in order to plan how the appointment will proceed. Where service users present with phobias/extreme anxieties or challenging behaviour, consideration to the following areas are a necessity in order to meet their health needs:

- Avoid waiting around as this may exacerbate anxiety levels/ challenging behaviour - first appointments should be offered.
- Where available, single rooms should be offered to minimise anxiety levels and avoid risks to other patients' safety.
- Sedation to be planned in advance as needed.

- Where the client is likely to exhibit challenging behaviour, the learning disability staff will liaise with the relevant nursing/medical staff to review how they can jointly manage these risky situations. It should not be assumed that the learning disability staff will manage all situations independently.

## **8.2 Day Surgery, including Ophthalmology Theatres**

(See **Appendix 3**, Elective admission also **Appendix 4** Theatre and Recovery)

- On receipt of the referral card, the Day Surgery Unit (DSU) will contact the patient with learning disabilities/carer to negotiate a date for a pre-operative assessment, and will request that the patient take the Patient Passport to the clinic appointment. If translation services are required this will be arranged by the unit, and if any specialist equipment is needed the unit will provide this for the clinic. Any special requirements for the patient will be identified at the pre-assessment clinic.
- The DSU will negotiate a date for surgery with the patient/carer that is mutually convenient. Transport requirements can be arranged at this point.
- On the day of surgery the service user/carer should bring the Patient Passport and hand to the named nurse who will be looking after the service user.

Provision will have been made for use of a side room if appropriate. Post-operative advice and support will be available via telephone on the Day Surgery Unit advice line Cumberland Infirmary, Carlisle 01228 523444 (Lead nurse for theatres and surgery Ext 4128), or West Cumberland Hospital 01946 693181 (Ext 4074).

## **8.3 Dental and Maxillo-Facial Department:**

There is a community dental service which is managed by the Primary Dental Care Team who offer outpatient and in-patient day-case facilities at the Cumberland Infirmary and West Cumberland Hospital. Should the learning disability team be aware of a patient with learning disabilities coming into the unit they should inform the department beforehand if possible to discuss any support needs. The contact number for the Senior Dental Nurse at the Cumberland Infirmary is 01228 608199, and for the Clinical Lead, Dental Services at Flatt Walks Health Centre, Whitehaven is 01946 695551 ext 245.

## **8.4 Routine Planned Admissions**

On receipt of the referral, the patient or carer should be contacted by the Consultant's secretary to negotiate date for admission with them.

Consideration should be given to combine procedures, wherever possible. During anaesthesia there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient.

The Pre-assessment appointment should be also planned, with as much time before admission as possible to ascertain information on patient and required care levels to disseminate to admitting ward.

The learning disability staff will negotiate between relevant carers and hospital staff to review all aspects of support needed within the hospital environment.

On admission, the 'Patient Passport' (where available) should be incorporated within the admissions procedure, with all relevant information, particularly that relating to specific support needs available and accessible to all ward staff.

Liaison between relevant disciplines, e.g. Occupational Therapy (OT), Speech and Language Therapy (SLT) and Physiotherapy (PT) will be established as needed and, if further support required, this will be agreed, e.g. joint working between community and hospital therapy staff. If joint working is agreed, clinical responsibility rests with hospital staff who will determine the appropriate treatment for the person with a learning disability, with Learning Disability clinicians providing a support role.

Medical secretaries will inform the learning disabilities team of any admissions for the forthcoming month where possible. Contact numbers are as follows: Cumberland Infirmary, Carlisle 01228 523444 medical secretaries Ext 4033, or West Cumberland Hospital 01946 693181 Ext 3007.

A list of all relevant North Cumbria University Hospitals contact names/telephone numbers is attached at **Appendix 10**.

## **8.5 Urgent or Emergency Admissions** (See **Appendix 5**, Emergency Admission)

Emergency admissions will usually be admitted via an out-patient clinic, or Accident and Emergency (A&E) Department.

It would be helpful for the service user, when admitted, to provide the Patient Passport to the clinic nurse or the nurse in charge in A&E who will then be able to assist the individual with his/her needs.

Accident and Emergency (A&E) admissions - if the learning disability staff are aware that a service user may need to access A&E, then they will contact the nurse in charge/consultant and/or identified contact within the A&E Department if it is anticipated that the service user may have some significant problems.

For service users with phobias and or challenging behaviours, as far as possible the above criteria (see **Appendix 5**, Emergency Admission) will need to be negotiated.

There will be emergency admissions of service users with learning disabilities that the learning disability team will not be aware of. In these circumstances the A/E department should contact the relevant community team and discuss how any apparent support needs can best be met.

## **9. DISCHARGE PLANNING**

On admission a service user and/or his/her carer should be advised of a provisional date for his/her discharge. This date will be reviewed on a daily basis and may involve a number of the hospital team. The nurse in charge will liaise with the individual and/or his/her carer about safe discharge to home from hospital.



The relevant staff should be informed of any admission of a person with a learning disability and dialogue established with the community team. Any factors which may prevent discharge back to the person's home should be considered as soon as possible.

Prior to discharge, a multidisciplinary meeting of all key parties (including family members as appropriate) involved in the care of the person should be convened to plan the discharge, especially where there has been a significant change in the service user's health needs. The learning disability staff involved may have to co-ordinate training for carers to manage the changing health need and/or review the need for temporary respite care or a permanent alternative placement.

The learning disability team will identify a contact person (this will usually be the community nurse) to liaise with the member of staff arranging the discharge.

## **10. SHARING INFORMATION**

All patients have a right to privacy and to control information about themselves. Where the person lacks capacity, this right must be balanced with protection of their interests. Although carers will be involved in best interests decisions there should not be widespread disclosure of personal health information without the person's valid consent and information should be shared on a need to know basis.

Information pertinent to any change in the person's support needs should be shared with learning disability care staff, but detailed clinical information should be treated sensitively and disclosed only when necessary and to those who need to know it.

It must not be assumed that the person's next of kin is the primary carer. Many people with learning disabilities live in registered care homes or supported environments and the care provider is responsible for the health and well being of the service user. Care staff would expect to be involved in best interests discussions where the person with a learning disability lacks capacity. Many people with learning disabilities have limited or intermittent contact with family members therefore care should be taken to ensure that information is disclosed appropriately and with the relevant people. Service users should be consulted about who they wish to be included in discussions about clinical matters. Clinical information will be shared as appropriate by professional colleagues, i.e. therapist to therapist, etc. to ensure continuity of care.

## **11. THE ROLE AND RESPONSIBILITY OF LEARNING DISABILITY STAFF WHEN SUPPORTING SERVICE USERS IN HOSPITAL**

People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. However, due to their complex care needs, they may require additional staffing support to meet their particular needs. The responsibility for providing medical and nursing care remains with the hospital but the learning disability service will offer to support service users as appropriate with issues related to their learning disability. This may include support with:

- eating and drinking
- communication

- taking medication
- managing behaviour
- reducing stress and anxiety.

At the point of admission, learning disability staff should ensure that all relevant information regarding the support needs of the service user is handed over to the named nurse/nurse in charge. The degree and frequency of any additional support required should be discussed, and agreement reached, as to how this will be provided out of existing or additional resources.

Learning disability staff will work alongside hospital staff, in agreement with the home manager and ward manager, to ensure that the service user's support needs are met. This support would include any personal tasks with which a residential support worker would normally be involved while caring for a person at home. It would not include nursing procedures.

Learning disability care staff should not be expected to agree to clinical procedures on behalf of the service user. Learning disability staff will also ensure that any specialist equipment that the service user needs is transferred to the hospital, e.g. seating systems, wheelchairs, eating and drinking equipment, communication aids etc.

## **12. FUNDING ISSUES IF ADDITIONAL SUPPORT IN HOSPITAL IS REQUIRED**

The purpose of this protocol is to identify how people with learning disabilities can best be supported to use the services provided by North Cumbria University Hospitals Trust. The protocol includes advice about the type of support that might be needed by some people but it does not describe in detail the procedure that should be followed in order to acquire any additional funding.

For service users who are registered with a North Cumbria GP there is an agreement that funding will be provided on application. This agreement identifies NHS Cumbria Acute Commissioning Team as having responsibility for the commissioning of any additional support required by people with learning disabilities who need a hospital admission. (See **Appendix 9.5.**) Applications for additional funding should be made to the Joint Commissioning Manager for People with Learning Disabilities on 01228 603590.

## **13. EVALUATION OF CARE & SERVICES**

North Cumbria University Hospitals Trust is interested in receiving feedback from all service users about the standard of care and services that they have received. An easy to read questionnaire is available on request.

## **14. CONCLUSIONS**

This protocol sets the context for hospital and community services to work together in meeting the health needs of this group of vulnerable people. It will enable more co-ordinated and individually tailored care to be provided, enabling people with learning disabilities to have their health needs met as fully as possible. It is anticipated that working in partnership with all relevant agencies in the health economy, joint training

and closer liaison will foster greater knowledge and understanding of the respective roles of hospital and community services.

## **15. RESPONSIBILITIES**

### **15.1 General Staff Responsibilities**

The wards at North Cumbria University Hospitals NHS Trust are managed by a matron, sister or charge nurse. Teams of nurses will provide twenty-four hour individualised care to meet the requirements of people with learning disabilities. In addition to nursing staff, like other patients, a person with learning disabilities will meet doctors on a regular basis and they may ask for Physiotherapists, Occupational Therapists, Dietician and Speech Therapists to assist in individual care. Following admission to hospital a Patient Passport (if available) will be passed to the ward area to which the service user is admitted and the nurse-in-charge will liaise with him/her and or his/her carer to discuss individual health requirements. The Matron or Senior Nurse, during daytime hours, Night Site Practitioner or Bleep holder at weekends will be the point of contact for any patient either admitted or using outpatient/day surgery facilities. This senior team will have received the appropriate training to take responsibility for co-ordinating and managing the care pathway for this group of patients and will communicate directly with the Learning Disability Team.

### **15.2 Line Manager Responsibilities**

The line manager is responsible for ensuring that they and their staff are aware of this protocol and that audits are undertaken to ensure compliance.

### **15.3 Equality and Diversity Committee Responsibilities**

The Equality & Diversity Committee will be responsible for ensuring:

- all staff are aware of this protocol.
- training for staff on caring for people with learning disabilities is available.
- monitoring and reviewing feedback from people with learning disabilities.

## **16. VALIDITY OF THIS POLICY**

This policy will be reviewed October 2011

## **17. AUDIT DETAILS**

See **Appendix 12**

## **18. REFERENCES**

Access to Healthcare Resources: (Information to Service Users)

Hollins S., Avis A., Cheverton S (1998) Going into Hospital, Gaskell / St George's Medical School, Books Beyond Words.

Hollins S., Bernal J., Gregory M (1998) Going to Out-patients, Gaskell / St George's Medical School, Books Beyond Words.

Valuing People: a new strategy for Learning Disability for the 21<sup>st</sup> Century – Department of Health (DoH), 2001.

Valuing People Now: From Progress to Transformation, 2009, 4 Key Principles of rights, independence, choice and inclusion.

All Means All – Valuing People Support Team (DoH), 2003

Valuing Health for All (PCTs and Health of People with learning Disabilities) – DOH 2003

Understanding the Patient Safety Issues for People with Learning Disabilities – National Patient Safety Agency (NPSA), 2004

Equal Treatment: Closing the Gap – Disability Rights Commission, September 2006, Royal College Psychiatrists.

Promoting Access to Healthcare for people with a learning disability – a guide for frontline NHS staff. Best Practice Statement. NHS Quality Improvement Scotland 2006

Making Decisions : Helping People who have difficulty deciding for themselves - A Guide for Healthcare Professionals - Lord Chancellors Department May 2003

Mental Capacity Act 2005, came fully into force 2007, Protects people who cannot make decisions for themselves due to Learning Disability or mental health conditions.

Learning Disability Taskforce: Rights, Independence, Choice and Inclusion, Jan 2004 DoH Publication.

Primary Care Service Framework – Management of Health for People with Learning Disabilities in Primary Care – Primary care and access to mainstream health services 2007.

Fair for All: Personal to You- consultation exercise about Choice in Health 2004, Valuing People Support Team.

Death by Indifference, Mencap.org.uk, March 2007, Report about institutional discrimination within the NHS, people with Learning Disabilities getting poor healthcare.

Commissioning Specialist Adult Learning Disability Health Services– Good Practice Guidance, DoH 2007.

Learning Disabilities Service Improvement 2008, follow on from Valuing People 2001 and Valuing People Now, Priorities for 2008-2009.

Valuing People Now: Transfer of Responsibility for the Commissioning of Social Care for Adults with Learning Disabilities from NHS to Local Government and Transfer of Appropriate Funding, August 2008 DoH, Gateway ref 9906.

Learning Disabilities Cumbria, Cumbria Local Area Agreement 2008-2011, Delivery Agreement.

North Cumbria University NHS Trust – Mental Capacity Act Policy – <http://nww.staffweb.cumbria-nhs.uk/acute/policies/mca.pdf>

Tips for effective spoken communication with people with a learning disability. [ Promoting access to healthcare for people with a learning disability –a guide for frontline NHS staff : NHS Quality Improvement Scotland 2006 ].

‘The Hospital Communication Book’, Learning Partnership Board, Surrey in conjunction with Valuing People – Helping to make sure people who have difficulties understanding and/ or communicating get an equal service in hospital. Covers pictorial representation of medical procedures, food and drink etc.

## APPENDIX 1 CORE PRINCIPLES

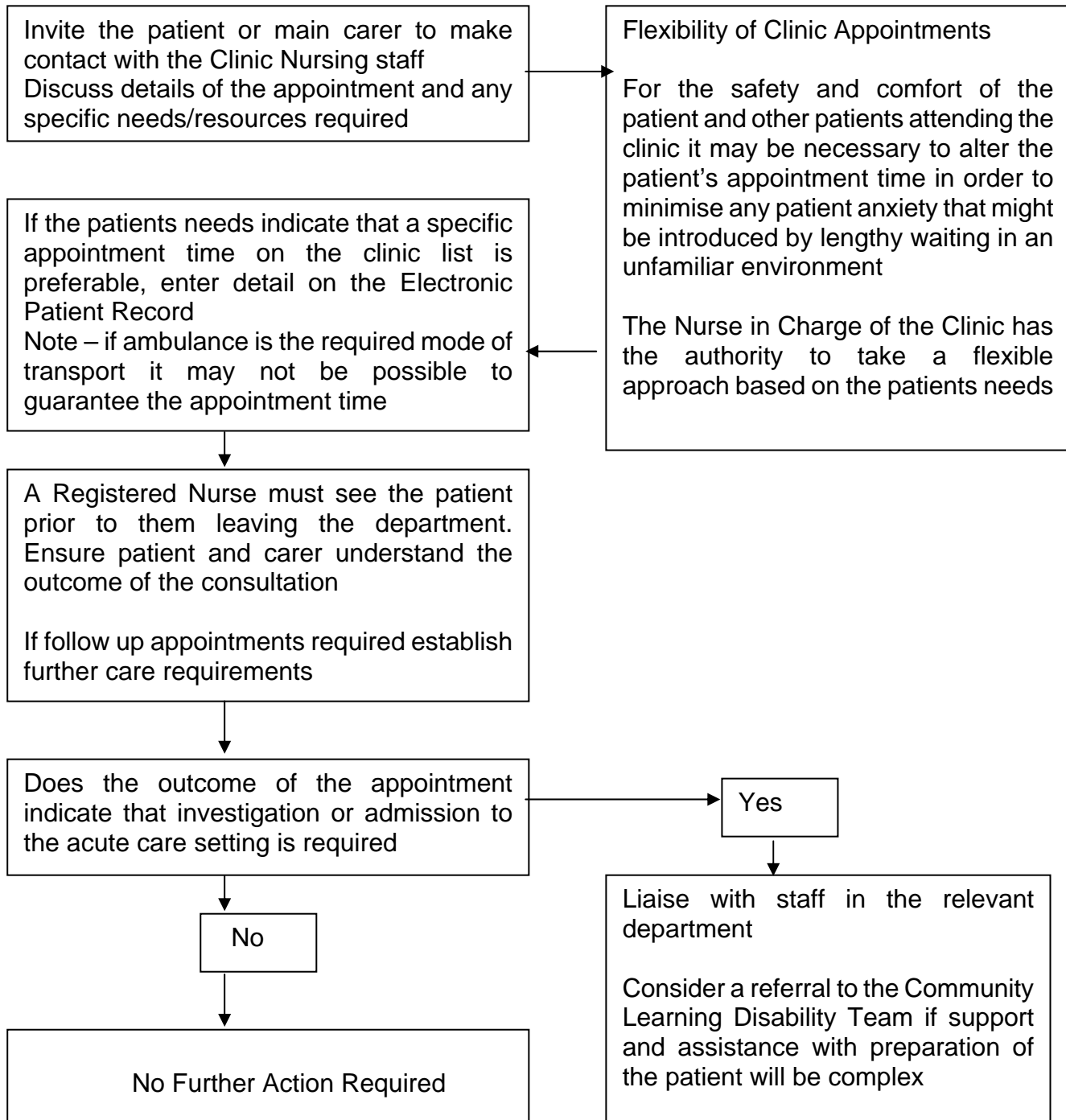
### CARE OF A PATIENT WITH A LEARNING DISABILITY IN NORTH CUMBRIA UNIVERSITY HOSPITALS NHS TRUST CORE PRINCIPLES



## APPENDIX 2 OUT – PATIENT ATTENDANCE

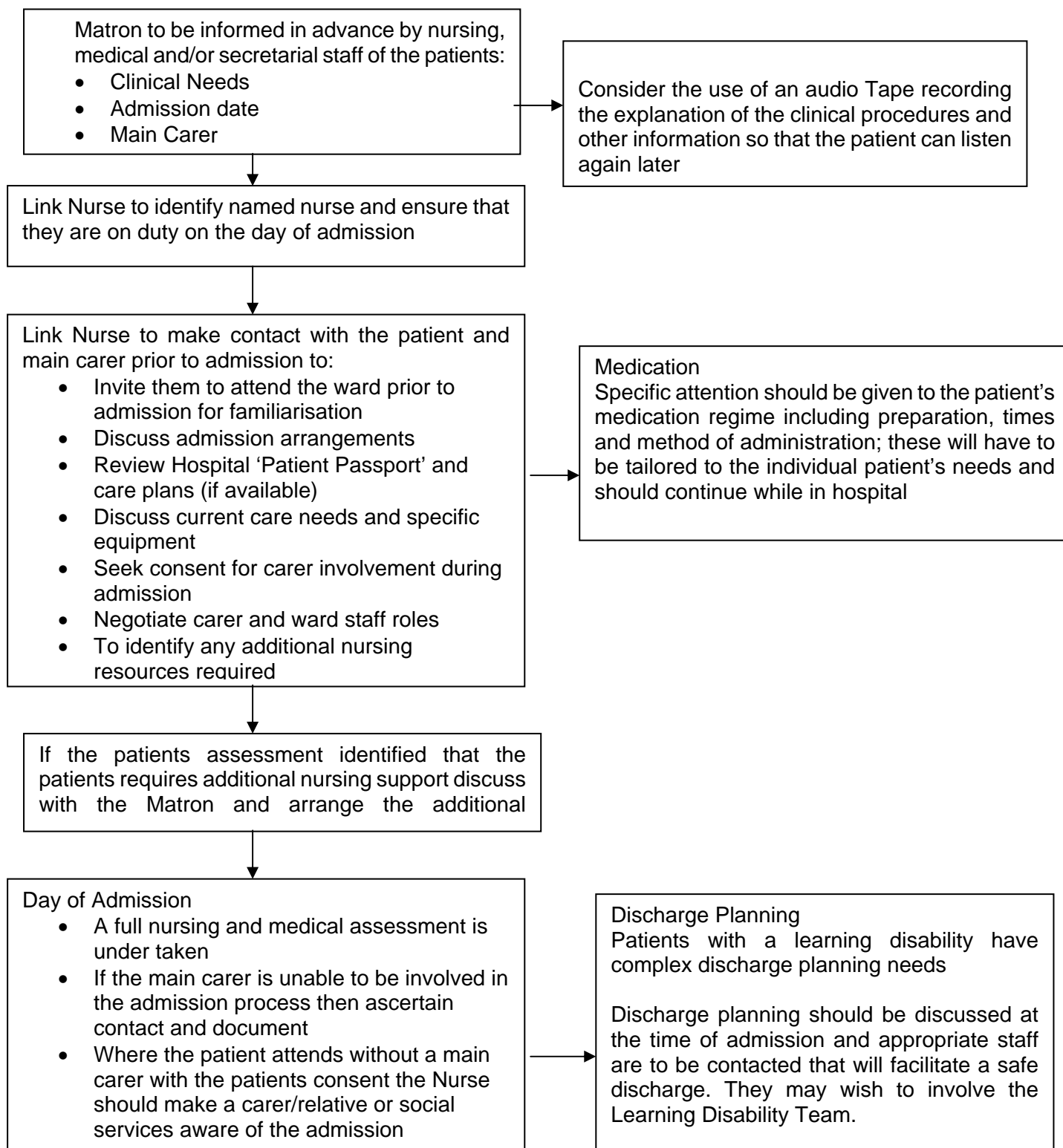
### CARE OF A PATIENT WITH LEARNING DISABILITY IN NORTH CUMBRIA UNIVERSITY HOSPITALS NHS TRUST

#### OUT-PATIENT ATTENDANCE



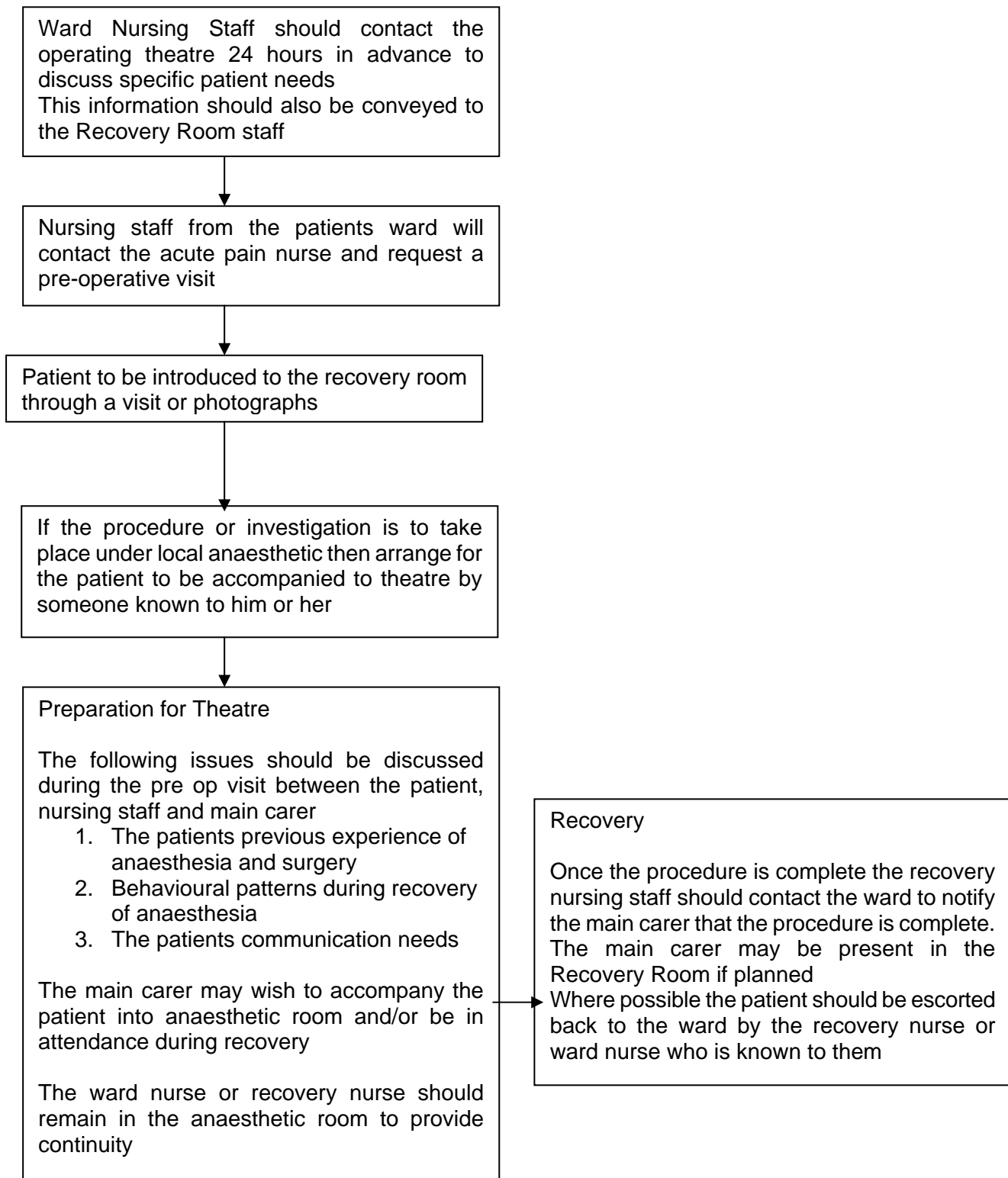
## APPENDIX 3 ELECTIVE ADMISSION

### CARE OF A PATIENT WITH LEARNING DISABILITY IN THE NORTH CUMBRIA UNIVERSITY HOSPITALS NHS TRUST ELECTIVE ADMISSION



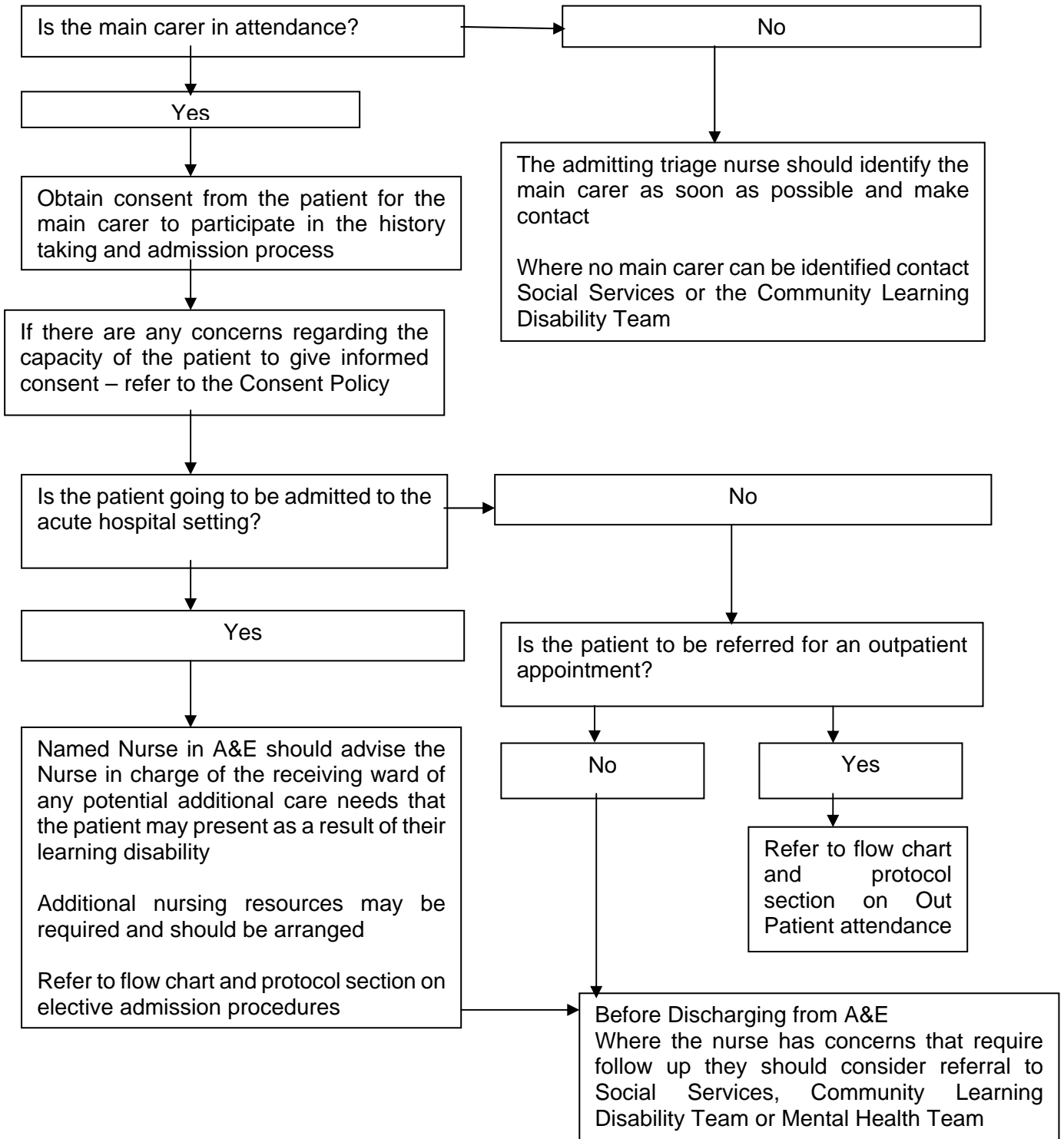


## APPENDIX 4 PATIENTS ATTENDING THEATRE AND RECOVERY CARE OF A PATIENT WITH A LEARNING DISABILITY IN THE NORTH CUMBRIA UNIVERSITY HOSPITALS NHS TRUST PATIENTS ATTENDING THEATRE AND RECOVERY



**APPENDIX 5 EMERGENCY ADMISSION**

**CARE OF A PATIENT WITH LEARNING DISABILITY IN THE NORTH CUMBRIA UNIVERSITY HOSPITALS NHS TRUST  
EMERGENCY ADMISSION**



## **APPENDIX 6 STRATEGIES FOR EFFECTIVE COMMUNICATION**

### **Strategies for Effective Communication**

- Speak slowly and clearly and avoid complex language.
- Check understanding
- Use short sentences and easy words.
- Use pictures and objects.
- Use gestures, body language and facial expression to supplement words but be aware that these may have different meanings across cultures.
- Avoid the use of technical words, jargon and abbreviations.
- Avoid the use of words which can have a literal meaning e.g. Wait a minute, take a seat.
- Avoid the use of complex instructions and spatial directions e.g. turn right at the end of the corridor and take the third door on the left.
- Be prepared for pauses and silences. People with learning disabilities may have difficulty processing information and formulating a response.
- Reduce distractions as far as possible.
- Supplement verbal information by the use of written instructions, symbols, pictures and objects.
- Use environmental and contextual cues where appropriate.
- Gather information from family members or carers as appropriate, but seek permission from the service user and continue to include them in the dialogue.
- Check if the person has a patient passport, communication passport or hospital book.
- Check the person's hearing status if possible, e.g. do they have a hearing aid?

Adapted from : Tips for effective spoken communication with people with a learning disability. [ Promoting access to healthcare for people with a learning disability –a guide for frontline NHS staff : NHS Quality Improvement Scotland 2006 ].

## APPENDIX 7 INFORMATION

# YOUR NEXT PATIENT MIGHT HAVE A LEARNING DISABILITY

### Pre-Admission

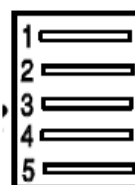
Check if I have a Health Passport.  
I may have specific guidelines [epilepsy, eating and drinking, dietary, allergies and behavioural etc] that you need to be aware of.



Give simple information

### Consent

Don't assume that I'm unable to make decisions for myself. I just might need extra help to understand. If I can't make a specific decision then consult all relevant people.



Help to remember

### Who May Need to Know That I am in Hospital?

**Family**      **Community Team**  
**Home Carers**  
**Befriender**      **Advocate**

Their advice may be very valuable to help you support me

### Discharge

Start planning for discharge as soon as possible into the admission. My needs may change. Carers may need extra training and support. New accommodation may be required.

**Please contact the relevant Community Learning Disability Team for advice and support. The Teams below are open during office hours 9am - 5pm; outside these hours leave a message on the ansaphone or send an email**

Community Learning Disability Team,  
Cedarwood,  
Carleton Clinic,  
Cumwhinton Drive,  
Carlisle,  
Cumbria  
CA4 0SX  
Tel: 01228 603189

Community Learning Disabilities Team  
The Old School  
Main Street,  
Distington,  
Cumbria,  
CA14 5UJ  
Tel: 01946 839840

## APPENDIX 8 HEALTH PASSPORT

This will be completed by the patient/carer before admission referring to the “How to Complete” booklet available to them. The ‘Plan for Going Home’ and the ‘Medication Needs’ sheet may be used prior to discharge.

### Health Passport for People with Learning Disabilities



<p><b>1. My Details</b></p> <p><b>My name</b> .....</p> <p><b>My Address</b> .....</p> <p>.....</p> <p>.....</p> <p><b>Postcode</b>.....</p> <p><b>Home tel no</b>.....</p> <p><b>Date of Birth</b>.....</p> <p><b>NHS Number</b>.....</p>
<p><b>My Primary Carer's name and relationship</b>.....</p> <p><b>My Primary Carer's Tel no</b>.....</p>
<p><b>My Community Learning Disability Team</b>.....</p>

**This passport is to let you know about my needs. I hope this helps you to understand me a little better and helps you with my care plan. This is a confidential document, it should be kept with my notes in hospital. Please return this passport to me when I go home.**

Date completed.....  
Completed by.....  
Date for review.....

**2. My next of kin..... Primary Carer- yes/no**

**Relationship.....**

**Address.....**  
.....

**Telephone Number.....**

**My next of kin can **not** make decisions on my behalf.**

**3. If you need to contact someone who knows me really well, please contact:**

**Name**..... **Relationship** .....

**Telephone Number**..... **Primary Carer:- yes/no**

**If you can't contact them, please contact:**

**Name**..... **Relationship**.....

**Telephone Number**.....

**Note for Hospital staff - These are the people to contact if you require any further information.**



**4. Name of GP**.....

**Practice**.....

**Telephone Number**.....



**5. Known Allergies:-**



**6. Date of last Tetanus:-**



**7. My medical history (any illnesses, injuries, operations, blood group etc)**







**10. I will need help with:**

**11. Things I can do for myself:**



**12. How often I normally go to the toilet to pass urine and to open my bowels.**



**13. Other people who help me are:**

**14. Things I like:**




**Things I dislike:**




**Extra Sheet 1, Fill this in just before going to the Hospital/Doctor**

**What is wrong now?**



**When was the last time you had anything to eat or drink?**



**Date and time extra sheet 1 completed.....**

**Completed by.....**

**Plan for going home**



**Date**

**Person responsible**

**Action**



## MEDICATION NEEDS

<b>PATIENT NAME AND DETAILS</b>		<b>GP SURGERY</b>
<b>WARD</b>		<b>SIGNIFICANT OTHER e.g. FAMILY, CARER, CARE AGENCY</b>
<b>My usual Community Pharmacy is</b>		
<b>How I usually take my medicines</b>	1. I take them independently 2. Carers prompt me to take my medicines 3. Carers give me my medicines	
<b>How I get my medicines</b>	1. I order and collect them myself 2. Someone helps me with ordering and collection	
<b>I have swallowing difficulties</b>	Yes / No	
<b>I need help with using medicines like creams or eye drops or inhalers</b>	Yes / No	
<b>I have problems with opening/closing containers</b>	Yes / No	
<b>I need help measuring liquids</b>	Yes / No	
<b>My reading and understanding of directions</b>	1. I can read and follow written and verbal directions 2. I can read directions but I may need some verbal direction to help me understand 3. I may have difficulty reading directions or remembering or following verbal directions	
<b>Other medicine needs</b>	1. using injections or suppositories                      Yes / No 2. managing multiple medicines or identifying multiple packages                      Yes / No 3. managing "if required medicines"                      Yes/No	
<b>Auxiliary Aids</b>	1. I need my medication in blister packs so that my carers can give me my medicines and I understand that this may not be a free service 2 I can use my medicines independently if I have blister packs or other auxiliary aids and the dispensing pharmacy should provide me with these for free as I qualify for this under the DDA (and am happy for the pharmacy to assess me for what aids I need) 3. I do not need any special aids for me to take or be given my medicines	
<b>Any other information:</b>		

(WCH PHARMACY 5/09 FS/GB)

## APPENDIX 9 FUNDING

### Protocol for the Funding of support if required by Adults with Learning Disabilities on Admission to Hospital

#### 9.1 Introduction

This protocol clarifies the funding arrangements for staff support, if required by an individual with a learning disability during an admission to hospital. It also recommends good practice in terms of the provision of that support.

The protocol has been agreed by North Cumbria University Hospitals NHS Trust, NHS Cumbria, the Cumbria Partnership NHS Trust, and the Provider Forum for Learning Disabilities.

#### 9.2 Principles

- People with learning disabilities have a right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive, and any diagnosis or treatment should take account of the specific needs generated by their learning disability.
- The responsibility for medical and nursing care provided to people with learning disabilities will remain with the hospital at all times during the patient stay.

#### 9.3 Background

A stated aim within the “Valuing People” and “Valuing People Now” White Papers are:-

“To enable people with learning disabilities to access a health service designed around their individual need, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary”.

and one of the Health Action points states

“..NHS to ensure that all mainstream hospital services are accessible to people with learning disabilities”.

The White Paper goes on to say:

“Mainstream secondary health services must also be accessible for people with learning disabilities. There must be no discrimination. Support will be needed to help people with learning disabilities admitted to a general hospital for medical or surgical treatment to help them understand and co-operate in their treatment. The NHS will ensure that all its procedures comply with the Disability Discrimination Act and that its staff recruitment and training practices are also fully compliant”.



## 9.4 Protocol

It is a clear aim that people with a learning disability have access to the same standard of care as the rest of the population during an admission to an acute hospital, and that this is the responsibility of the NHS

However, for some people with a learning disability, their complex care needs may require additional staffing support during their stay. This may be as a result of communication or comprehension difficulties, sensory impairment, mental health needs, or behavioural problems.

The assessment of whether an individual requires additional staffing support should be undertaken by the Care Manager, in liaison with any relevant health professionals within the Community Learning Disability Team, or the person who best knows the patient.

Under these exceptional circumstances, if an individual does require extra staffing support to enjoy the general standard of care, this should be the responsibility of the Learning Disabilities Strategy Manager to commission.

Where possible, any requirement for extra support should have the prior authorisation and agreement of the Learning Disabilities Strategy Manager within NHS Cumbria Trust. In situations of emergency admission, the Learning Disabilities Strategy Manager should be informed as soon as possible.

In order to assure the best possible experience for the patient, it would be preferable in most cases that the actual staff support is known to him/her. This would mean that the organisation supplying the staff member would reclaim the cost from the Primary Care Trust budget.

For planned admission to hospital, the extra support required would be arranged through the Adult Social Care Team.

In these cases, appropriate planning should have taken place, to ensure that hospital staff are aware of the specific needs of an individual patient, and agreement as to any level of extra staffing support would have been reached.

In the case of an emergency admission, the Adult Social Care Team would attempt to arrange the extra staffing required as soon as possible.

## 9.5 Process

All requests for planned additional support/notification of emergency additional support should be submitted to the Team Managers for Learning Disabilities by e-mail and should include the following information:

- Client name
- Client home address
- Client date of birth
- Name of the hospital where the additional support is to be/has been (in case of emergency admission only) provided
- Reason for admission
- Planned admission date and expected length of stay (in the case of an emergency admission please state whether or not the client has been discharged at the time of notification).
- Reason for additional support (e.g. manage challenging behaviour)
- Expected duration of support
- Estimated cost of support
- Care Manager's name and contact details

Requests for planned support should be submitted as soon as the planned admission dates are known. Notification of emergency admission should be made preferably within 48hours.

The Learning disabilities Strategy Manager will confirm funding to the Head of the Adult Social Care Team, Learning Disabilities within five working days of the receipt of the request/notification.

Providers of additional care should be instructed to submit invoices in respect of confirmed funding direct to:

The Learning Disabilities Strategy Manager  
4 Wavell Drive,  
Carlisle  
CA1 2SE  
Tel: 01228 602000

Invoices should detail:

- Client name
- Hospital where support was provided
- Dates when support was provided
- Name of Care Manager who negotiated funding

All invoices should be submitted within 6 weeks of the completion of the episode of support.

## 9.6 General

In the event that any issues should arise regarding facilities for carers of people with learning disabilities during a hospital admission these should be brought to the attention of Patient Advice and Liaison (PALS).

## APPENDIX 10 CONTACT DETAILS

### Hospital Contact Names/Telephone Numbers

#### CUMBERLAND INFIRMARY

##### Senior Clinical Nurses/Matrons

<b>TITLE</b>	<b>CONTACT NUMBER</b>
Lead Matron for Cumberland Infirmary, Carlisle	01228 523444 via Switchboard
Matron of Surgery & Orthopaedics	01228 523444 via Switchboard
Matron of Medicine, EMAU, and A&E	01228 814430
Lead Nurse, Theatres	01228 523444 Ext 4238
Matron of Renal Unit (Willow B)and Elderly Care	01228 523444 via Switchboard
Lead Nurse, CCU (Willow A) & ITU	01228 814114
Lead Nurse, Paediatrics/SCBU	01228 814271
Matron of Maternity	01228 814266
Lead Nurse for Dermatology – CIC	01228 523444 Ext 4156
Lead Nurse, Outpatients	01228 523818 via Switchboard
Lead Nurse, DMPU	01228 523444 via Switchboard

Departments

<b>DEPARTMENT</b>	<b>TITLE</b>	<b>CONTACT NUMBER</b>
Breast Screening	Breast Screening Services Manager	01228 81436
Diabetes	Diabetes Specialist Nurse	01228 814780
Dietetic and Nutrition	Dietetic Service Manager	01228 814793
Dental - Orthodontic	Lead Nurse	01228 814201
Dermatology	Lead Nurse	01228 814156
Disablement Services	Head of Department	01228 814783
Endoscopy	Lead Nurse	01228 814328
Medical Physics	Head of Department	01228 814701
Occupational Therapy	Principal Occupational Therapist	01228 814440
Pathology	Head of Department	01228 814511
Pharmacy	Head of Department	01228 814537
Physiotherapy	Lead Physiotherapist	01228 814737
Radiology	Superintendent Radiographer	01228 814133
Speech and Language Therapy	Lead Nurse	01228
Patient Advice and Liaison PALS	PALS Officer	01228 814008

## WEST CUMBERLAND HOSPITAL, WHITEHAVEN

Senior Clinical Nurses/Matrons 01946 693181

<b>TITLE</b>	<b>CONTACT NUMBER</b>
Lead Matron, WCH	Ext 3048
Matron Surgery/Orthopaedics	Ext 4201
Matron EMAU, A&E, & Medicine	Ext 3008
Lead Nurse, Theatres	Ext 3491
Matron, Elderly Care	Ext 3089
Lead Nurse, ITU & Ophthalmology	Ext 3443
Lead Nurse Paediatrics/SCBU	Ext 4164
Matron, Maternity	Ext 4246
Lead Nurse, Outpatients	Ext 3296

Departments 01946 693181

<b>DEPARTMENT</b>	<b>CONTACT NUMBER</b>
Breast Screening	ext 4368
Diabetes	ext 3009
Diet and Nutrition	ext 3400
Dental	ext 3293
Disablement Services	ext 4096
Endoscopy	ext 3061
Medical Physics	ext 3456
Occupational Therapy	ext 3626
Pathology	ext 3424
Pharmacy	ext 3468
Physiotherapy	ext 3637
Radiology	ext 3347
Speech and Language Therapy	ext 2907
Patient Advice & Liaison Service (PALS)	ext 3818

## APPENDIX 11 MEMBERSHIP

### Membership of Protocol Group

Janice Moscrop	Acting Deputy Director of Nursing, North Cumbria University Hospitals NHS Trust (Acute).
Sue Munson (Chair)	Health Pathway Coordinator, Cumbria Learning Disabilities NHS Foundation Trust.
Fiona Dixon	Manager for Learning Disabilities, Cumbria Partnership Foundation NHS Trust.
Denise Jarman	Operations Manager, The Glenmore Trust on behalf of the Provider Forum.
Susan Gorman	Learning Disabilities Team Leader, Cumbria Partnership NHS Foundation Trust.
Julie Graham	Cumbria Partnership NHS Foundation Trust, Team Leader (South), Learning Disabilities Team Acting Service Manager.
Muriel Nixon	Adult Social Care Cumbria, Learning Disabilities Strategies Manager
Linda Turner	Senior Community Nurse, Learning Disabilities (South) Cumbria Partnership NHS Foundation Trust.
Sue Cowperthwaite	Family and Carer Representative.
Gill Berry	PALS Officer, North Cumbria University Hospitals NHS Trust (Acute).



## APPENDIX 12 AUDIT TOOL



### Audit Tool Guidance

#### STATEMENT

The Trust will work towards effective Governance and to demonstrate this, regular audits against policy compliance will be carried out. Policy authors will be encouraged to attach audit tools to their policies.

It is suggested that there are three standard statements to each audit tool and that the author will identify a minimum of 5 audit statements to ensure compliance and efficacy against the policy. Members of staff from each hospital site will be selected to assess the audit tool statement questions and the findings of the audit will be reported on the Clinical Audit & Effectiveness Committee.

Policy title		Yes %	No%
Standard Statement		Yes %	No%
Statement 1	Are staff aware of this policy?		
Statement 2	Do staff know how to locate policies on staff web?		
Statement 3	Have staff had any formal / informal training in using computer to access the staff web?		
Statement 4	Have staff had training on how to look after people with learning disabilities?		

