



# National Drugs Management Scheme

## Patient Information Leaflet

### Hospital Based Multiple Sclerosis Treatments

This leaflet will provide you with information about how some of your details may be collected to support the new National Drugs Management Scheme and your rights under the Data Protection Act.



## National Drugs Management Scheme

The National Drugs Management Scheme (NDMS) was set up to ensure equitable access for patients to specified high-cost drugs. The initial focus is on providing centralised reimbursement for two specific multiple sclerosis drugs, natalizumab and alemtuzumab.

The NDMS is operated under the Acute Hospitals Drugs Management Programme (AHDMP) which is part of the Health Service Executive (HSE).

### Why is my personal information being used?

To have a clear picture about multiple sclerosis drug treatment in Ireland, we need to match the drug treatment you are receiving with your diagnosis. We also need to monitor usage of the drugs to ensure we are able to plan for and predict future need. This means that some of your personal details are collected. This information will help the AHDMP to:

- Make sure that your treatment is of the same high standard regardless of where you are residing in Ireland.
- Improve the care given to all multiple sclerosis patients through clinical audit.
- Look at how well certain drugs are working.
- Make sure that when new drugs become available in Ireland they are used in line with best practice.
- Process payments to hospitals for multiple sclerosis drugs.

To do this, information is collected about the diagnosis you have received and the drugs that your doctor has prescribed to you. The AHDMP will only use your information as set out in this leaflet.



### **What personal information will be collected?**

All information that is collected is treated in the strictest confidence.

The information collected is:

- Your name, address and date of birth,
- Your diagnosis,
- Information about the drug you are receiving,
- Your Medical Card number or Long Term Illness Card number or Personal Public Security Number (PPSN) and your hospital Medical Record Number (MRN).

This programme is approved by the Department of Social Protection for the collection of the PPSN.

### **How will my decision be recorded?**

If you are happy with the information you have received in this leaflet, have had the chance to ask questions and you are happy with the answers, a member of staff from your hospital may ask you to provide your written consent. However, if you advise a member of your nursing or medical team that you don't want your personal information to be used, this will be noted. This will not affect your treatment.

### **How will my information be used?**

Your information will be entered into a secure computer system by a member of staff of the hospital. The computer system belongs to the Primary Care Reimbursement Service (**PCRS**). PCRS are experts in managing confidential patient information, such as the drug payment scheme for medicines bought in chemists in your community. Access to the computer system is password protected and accessible to authorised personnel only.

You will not be named in any information provided by PCRS to the Acute Hospitals Drugs Management Programme (**AHDMP**). You will not be named in any reports produced by NDMP. It is expected that your information will be kept for a period of up to a five years to allow for clinical audits which will help us to improve services.

### **Who will have access to my personal information?**

Only a small number of health service staff will have access to your personal information. These staff work in your hospital and in the PCRS.

### **Your Rights under the Data Protection Acts 1998-2003**

You should be aware of the following rights that you have in relation to the Data Protection Acts 1998-2003. These rights include:

- The right to have your personal data processed in line with data protection legislation.
- The right to information about your personal data.
- The right to access your personal data.
- The right to know how your personal data is being processed.
- The right to have your personal data amended or deleted if appropriate.

If you wish to exercise any of the rights listed above, you can contact a member of your medical or nursing team or the Data Protection Officer in your hospital. The HSE's National Complaints Governance and Learning Team can also give you advice and their contact details are below.

### **Contact Information for HSE FOI & Data Protection Management**

Mr Donal Devery, HSE National Lead, Block 4, Central Business Park,  
Clonminch,  
Tullamore,  
Co. Offaly

Email: [emma.kelly@hse.ie](mailto:emma.kelly@hse.ie) and Tel: 057 9357610

### **HSE's National Complaints Governance and Learning Team**

National Quality Assurance and Verification Division,  
HSE, Oak House, Limetree Avenue, Millennium Park,  
Naas,  
Co. Kildare

Email: [yoursay@hse.ie](mailto:yoursay@hse.ie)

Tel: LoCall No: 1890 424 555

*This leaflet will be reviewed and updated as new information emerges. While every effort has been made to ensure that it is accurate, we do not accept responsibility for errors or omissions.*