



# Dysmorphology Diagnostic System (DDS)

## Patient Information & Consent Form

Please print 2 copies of this form.

One copy should be given to the patient/legal guardian for their information.  
The second, signed copy of this form should be kept in the patient's records.

**DYSCERNE: A Network of Centres of Expertise for Dysmorphology**  
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[www.dyscerne.org](http://www.dyscerne.org)



European Commission Public Health Executive Agency (DG Sanco) Project: 2006122

- A European Network of Centres of Expertise for Dysmorphology

# What is DDS?

DDS stands for Dymorphology Diagnostic System.

Your doctor would like to use the DDS to help them diagnose your or your child's condition. They will discuss this process with you, but this information sheet will also explain what is involved.

The DDS is part of the DYSCERNE project. DYSCERNE is a European project which will improve the diagnosis and management of rare dysmorphic conditions.

It is your choice whether you want the doctor to use the DDS. Please take time to read through the following information. If anything is unclear, please ask questions.

## What is dysmorphology?

Dysmorphology is a medical speciality. Experts in Dysmorphology can recognise that a child born with a distinct pattern of physical and/or learning disabilities has a particular medical condition (or syndrome).

Children diagnosed with a particular syndrome will have similar patterns of physical features, growth, development and behaviour.

Some syndromes are very rare and even experts must consult each other before making a diagnosis.

## What is the purpose of the DDS?

The electronic Dysmorphology Diagnostic System (DDS) will improve communication between specialist doctors. Ultimately, this will help rare conditions to be diagnosed.

Having a diagnosis makes sure you receive appropriate care and counselling on recurrence risks, and may also help with access to new treatments.

There may also be opportunity to contact a patient support group or other families where the same condition has been diagnosed.

## **What information will be sent to DDS?**

For the DDS Expert Panel to give an accurate opinion they need detailed medical histories & clinical photographs.

This is because in many cases people with dysmorphic syndromes have a distinctive pattern of facial and other features.

## **What happens to the information sent to DDS?**

The DDS will link an electronic network of European experts (the DDS Expert Panel) who specialise in the study of dysmorphology.

These experts will look at your medical history and send opinions on possible diagnoses and plans for further investigations or management to the coordinating centre.

The coordinating centre, based in Manchester, UK (for full address see the front of this leaflet), will collate the expert opinions into a report. We will send this report to your doctor who will discuss the report with you.

## **Who will see your medical information and photographs?**

Your medical history and photographs will be seen by the doctor who submits your case, the DDS Administrators at the coordinating centre, and members of the Expert Panel.

Medical histories and photographs sent to DDS will be secure and confidential. Your name will not be disclosed to the Expert Panel and they will only see information that is relevant to your case. All photographs submitted to DDS will be electronically 'watermarked' and password protected to prevent unauthorised use.

# What options do I have?

The consent form at the back of this leaflet is for you to complete if you would like your/your child's medical history to be submitted to the DDS for review by the Expert Panel.

The consent form asks if you agree to the following:

- 1. That a medical history and photographs can be sent to the DDS**
- 2. That this information can be stored in the DDS Archive.**  
The DDS Archive is a valuable resource and will be used by DYSCERNE's Doctors to assist in the identification of new conditions and increase knowledge about existing ones.
- 3. That this information may be presented at scientific meetings.**

Selected cases from the Archive may be presented at scientific meetings to educate doctors about dysmorphology and the DYSCERNE Network. Your name and other personal information would not be used.

You choose how your medical history and photographs can be used. If you do not agree to options 2 and 3, your case can still be sent to the DDS for the Expert Panel to review.

**You can notify the DDS administrator at any point in the future if you change your mind. The DDS Administrator can be contacted at the address on the front of this leaflet.**

## **What happens next?**

If you are happy for your doctor to send your medical history and photographs to the DDS please complete and sign 2 copies of the DDS Patient Consent Form at the back of this leaflet.

One copy should be returned to your clinician, the other is for you to keep.

## **Where can I find out more?**

You can contact us at the address or telephone number on the front of this leaflet.

There is more information about DYSCERNE and the DDS on the internet at **[www.dyscerne.org](http://www.dyscerne.org)**

## **Data Protection**

The DDS Expert panel is made up of expert dysmorphologists from EU and non-EU member countries. Data Protection legislation is uniform throughout the EU but may vary in non-EU countries.

We will ensure that there is an adequate level of data protection before we pass your information to an Expert Panel member.

The University of Manchester, UK is a registered Data Controller with the Office of the Information Commissioner (Reg. Number: Z6787610). All personal data held by the University is processed in accordance with the principles of the Data Protection Act 1998.

**Thank you for reading this information leaflet**

**To clinician, please enter your local contact details here:**

# Dysmorphology Diagnostic System (DDS) Patient Consent Form

If you wish your doctor to send medical details to DDS please complete this form, ticking the appropriate boxes and return it to your doctor.

I have read the DDS Patient Information leaflet and been given the opportunity to ask questions:		Yes <input type="checkbox"/>
		No <input type="checkbox"/>
I give permission on behalf of myself/my child/legal ward		(insert name of patient)
Patient/Hospital Reference No:		
Patient Date of Birth:		
To Dr/Prof	(insert name of clinician)	
of the		
(insert Department address)		
1. I agree that a medical history and photographs regarding myself/my child/legal ward can be sent to the DDS		<input type="checkbox"/> ►
2. I agree that the medical history and photographs sent to the DDS can be stored in the DDS Archive		<input type="checkbox"/> ►
3. I agree that the medical history and photographs stored in the DDS Archive may be used at scientific meetings		<input type="checkbox"/>

► If you choose these options your medical history and photographs will be treated in the strictest confidence and seen only by the doctor who submits your case, DDS Administrators and members of the Expert Panel.

If at a later date you would like your medical history and photographs removed from the DDS Archive, please contact the DDS Administrator in writing, at the address below.

*By completing this form you are consenting to The University of Manchester processing your/ your child's/legal ward's personal data for the purposes you agreed to above, as set out in the DDS Patient Information Leaflet.*

Signature of patient /parent/legal guardian	Date:
Please state your relationship to the patient (e.g. self, mother)	
Signature of clinician seeking consent	Date:

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### DYSCERNE Partners:



INSTYTUT  
 „POMNIK - CENTRUM ZDROWIA DZIECKA”



THE CHILDREN'S MEMORIAL HEALTH INSTITUTE



Assistance Publique  
 Hôpitaux de Marseille

### Supporting Organisations:



European Commission Public Health Executive Agency (DG Sanco) Project:  
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