

Data Protection Statement

- The DYSCERNE lead partner, the University of Manchester is a registered Data Controller with the Office of the Information Commissioner (UK) under Registration Number: Z6787610. All personal data held by the University in electronic, manual and digital form or format is processed in accordance with the eight principles of the Data Protection Act 1998 and in accordance with the rights of Data Subjects under Section 7 of the Act.
- The eight principles of the Data Protection Act 1998 say that personal data must be:
 1. Fairly and lawfully processed;
 2. Processed for a limited period only;
 3. Adequate relevant and not excessive;
 4. Accurate and up to date;
 5. Not kept for longer than necessary;
 6. Processed in accordance with individual's rights;
 7. Secure;
 8. Not transferred to countries outside the EEA unless the country has adequate protection for the individual.
- DYSCERNE will only use data for the purposes stated below.

Patient data held on the Dysmorphology Diagnostic System (DDS)

- Informed Consent must be obtained before a patient's personal data can be entered into the DDS.
- It is the responsibility of the submitting clinician to ensure that informed consent has been obtained and that the appropriate level of consent is selected on the DDS case submission form in accordance with the patient's wishes. Case submission forms where a consent level has not been selected will be returned to the submitting clinician.
- Patient information will only be used for the purposes of diagnosis and/ or improving patient care and management.
- In the DDS each patient's information will be identified by a unique reference number.
- Expert Panel members will only see anonymised patient information.
- After being reviewed by the DDS Expert Panel, a patient's personal data will be removed from the system unless the patient has consented to their data being stored on the DDS archive.
- Where patient information is held in the DDS archive, DYSCERNE will request periodic updates from the submitting clinician.
- If a patient decides they would like their personal information removed from the DDS archive, they can contact the DDS administrator either directly or via their clinician.
- When patient information is deleted from the DDS a record will remain that a medical history was submitted but all personal information will be removed from the system.
- Transfer of data outside the EU/EAA
 - The DDS Expert panel is made up of expert dysmorphologists from EU and non-EU member countries.

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- While data protection legislation is uniform throughout the EU it may vary in non-EU countries.
- DYSCERNE will ensure that there is an adequate level of data protection before passing patient information to an Expert Panel member, see 'Security of Data' below.
- DYSCERNE will require Expert Panel members from non-EU countries to sign a 'confidentiality contract' which will contain the EC 'standard contractual clauses for the transfer of personal data to processors established in third countries'.
- Where a non-EU country's data protection regime has been recognised by the European Commission as offering adequate data protection, Experts in that country will not be required to sign a 'confidentiality contract'.

Clinicians' registration information held on the DDS and the Educational Resources database

- Clinicians registered with DYSCERNE for the purpose of accessing the DDS or the Educational Resources, can change their own personal account information at any time.
- If a clinician with a DDS account moves institution, their DDS account will be deleted. They can then register for a new DDS account under their new institution.
- DYSCERNE will not pass personal account information onto third parties.
- Anonymised account information may be used for audit purposes.
- DYSCERNE may contact registered clinicians to ask for feedback on the DDS / Educational Resources. Information gathered in this way will be anonymised and used to improve the DDS / Educational Resources in the future.
- Occasionally DYSCERNE may contact account holders with information about the DDS / Educational Resources or more general information on the DYSCERNE project.
- A registered clinician's personal information can be removed from the DDS or Educational Resources database by contacting the relevant administrator (DDS administrator for the DDS or DYSCERNE project support assistant for the Educational Resources), however their account will then be cancelled and they will be unable to access the DDS/ Educational Resources.

Security of Data

- The DDS operates to a high level of security including data encryption and is subject to annual server security certification.
- Data storage areas are physically secure and accessible only to authorised staff.
- Data is stored in private, secure file directories. Access to these directories is password protected.
- All patient information and clinical photographs submitted to the DDS will be secure and confidential.
- Clinical photographs submitted to the DDS will be electronically 'watermarked' and password protected to prevent unauthorised use.