NHS
Connecting for Health

Personal Demographics Service (PDS)

A guide for general practice

Contents

1. Introduction

The Personal Demographics Service (PDS) is the national electronic database of NHS patient demographic details (see Appendix 1), used by NHS organisations.

The PDS enables a patient to be readily identified by healthcare professionals and associated, quickly and accurately, with their correct medical details. The PDS does not hold any clinical health record information or other sensitive data items such as ethnicity or religion.

The Personal Demographics Service is an essential element of the NHS Care Records Service (NHS CRS[1]) which will underpin the creation of an electronic care record for every registered NHS patient in England by 2010.

---

[1] http://www.nhscarerecords.nhs.uk

The PDS will gradually integrate and replace several existing NHS demographic databases including the:

- NHS Strategic Tracing Service (NSTS)
- NHS Number for Babies (NN4B)
- NHS Central Register (NHSCR)
- National Health Applications and Infrastructure Services (NHAIS)

The PDS will also replace many locally-held NHS databases, providing a single accessible, efficient, reliable and integrated electronic demographics service. Changes made in one location will be available for access across NHS Care Records Service systems without delay. Instead of different organisations creating and maintaining multiple records for patients with duplicated demographic items (for example multiple addresses), there will be a single up-to-date and definitive demographic record for each patient for authorised NHS professionals to access and use.

The PDS offers several key advantages to users, including faster access, better communication between NHS organisations and less risk of duplication or mis-identification of patients.

Key benefits of the PDS are:

- Improved patient safety through a reduction in the number of errors when matching patients and episodes of patient care.
- A more convenient way to add or update demographic information such as contact details. Eventually patients themselves will be able to check their details and update some of them using HealthSpace[2], a secure NHS web service for people who live in England.
- Quicker, more convenient access to accurate and complete patient demographic information (such as contact details, registered GP) and correct matching to each patient's NHS Care Record.
- A reduction in the amount of correspondence going to the wrong address.
- More difficult for patients to use 'ghost addresses' to enable them to remain registered with a practice.

[2] http://www.healthspace.nhs.uk

2. *Access and Security*

Only authorised healthcare professionals with a Smartcard[3] and passcode who have been granted appropriate access permissions will be able to access the PDS. Controlling general practice access to the PDS is the responsibility of each Primary Care Trust (PCT) acting as a Registration Authority.

PCT Information Governance (IG) staff, working with practices, are responsible for setting access permissions on staff Smartcards in their local general practices. Information contained within a patient's demographic record is only available to an NHS professional where they meet all of the following criteria:

- they are authorised to use the system
- they have located the patient using their demographics details or NHS Number
- there is a proven and justified business reason for doing so.

Access to a patient's demographic record does not require a Legitimate Relationship[4]. [However, having identified the patient in the PDS, access to a patient's recorded clinical information does require a Legitimate Relationship].

Further restrictions are required for some patients' demographic information including for:

- anyone who feels that their demographic details should not be accessible by the NHS
- adoptions
- gender reassignment
- other situations where vulnerable patients request restricted access.

There may be some cases where restricted access is overridden, for example when there is a police investigation into a serious crime. Further details of the system for handling such sensitive records are given below.

---

[3] http://www.connectingforhealth.nhs.uk/systemsandservices/rasmartcards

[4] Legitimate Relationships control who has access to a patient's sensitive personal data - broadly equivalent to identifiable information within a patient's clinical record.

All healthcare professionals have a duty of confidentiality to their patients and must comply with legal, ethical and contractual obligations[5]. Inappropriate and unlawful possession of confidential patient information could lead to disciplinary action including dismissal, litigation and for health professionals, sanctions by professional regulatory bodies.

Healthcare organisations, including general practices, are responsible for establishing appropriate and effective information governance procedures, supported by their PCT. Each healthcare organisation is responsible for ensuring that:

- healthcare professionals understand and meet information governance standards
- information governance controls are implemented effectively
- healthcare professionals are aware that inappropriate use of the PDS could result in disciplinary proceedings against them
- procedures are in place for auditing use of the PDS and responding to any alerts generated by the system.

Information governance controls protecting patient information include:

- The registration and authentication process.
- Role based access controls, linked to the identity of each authorised healthcare professional, specifying what users can see and do when logged into the system.
- Search controls constraining how users are able to look up the details of individual patients.
- Sensitive record controls preventing users from accessing PDS information when records are flagged as sensitive. In these cases the patient's address, telephone numbers and GP registration will not be returned by the PDS.
- Tools for auditing which users have viewed or amended PDS records, and local supervision by 'privacy officers' to assure proper use. In the case of PDS, records are kept of the following actions:
    - o tracing, retrievals and confirmation of an NHS Number
    - o updates (additions, amendments etc.)

---

[5] NHS Confidentiality Code of Practice http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253

- allocation of NHS Number
- merges of demographic information.

3. Data Quality

The great strength of the Personal Demographics Service is its ability to identify and link each NHS patient in England to a care record uniquely associated with each patient. In order to achieve this, however, there will be a greater responsibility and reliance put on staff working within the NHS to check and maintain accurate information.

For new patient registrations, the story begins when the patient completes a GMS1 form (see Appendix 2). Currently, the details from the GMS1 form are entered into the GP's computer system and then submitted electronically to the NHAIS system (also known as the Exeter system) for approval by the patient data team in the PCT (or agency operating on behalf of one or more PCTs) to create a new electronic GP record for each patient.

PCT staff use the NHAIS system to review and accept the data provided from the surgery. If no NHS number is provided, PCT staff use the PDS to identify the patient's demographics record and determine their NHS Number. This information is then used to enable the transfer of the patient's medical record from their previous GP.

NHS CFH is working with GP system suppliers to fully integrate their systems with the PDS. This means that for fully integrated systems the user (normally a member of the practice's administrative staff) will trace the patient against the PDS when registering them with the practice. This means the user can select the correct patient quickly and reliably, speeding up the process and reducing the likelihood of errors. If the patient cannot be found on the PDS, then the user can ask the patient supplementary questions (for example "how do you spell your name?") to ensure that the correct PDS record is found.

Where a GP system is not fully integrated, matching the patient to the information entered into the system occurs at the primary care back office. As the patient is not present, there is wider scope for errors to be made. Therefore, it is important that the GMS1 form is completed accurately and in as much detail as possible to ensure that the correct information is accurately transcribed to the GP system. GP practices should therefore ensure that:

- The GMS1 form is checked in the patient's presence to ensure that it is readable, accurate and complete (see Appendix 2). This should include the patient's previous address where they were last permanently registered, in order to help locate their exact record.
- The GMS1 is accurately transcribed into the GP system.
- If known, the patient's NHS Number[6] is normally used. For babies[7] this can be found on the discharge form or on form FP58).

It is therefore extremely important that the information provided is accurate and complete. Determining a patient's NHS Number is entirely dependent upon the quality of information provided by the GP practice. If incorrect or insufficient information is provided:

- The patient's demographic record may not be found. A new record will be created and, until this is resolved manually, there will be a delay in the transfer of the patient's medical record; or
- The patient may become mis-associated with another patient's demographic record, resulting in confusion of the patient's personal details and in time, the patient's clinical health record data. This may delay or confuse treatment at a later date and may delay the registration process, restricting access to NHS CRS services such as Choose and Book or the Electronic Prescription Service.

4. *PDS National Back Office*

The PDS National Back Office (PDS NBO) has evolved from the existing NHS Central Register service which was provided to the NHS by the Office for National Statistics. Together with local primary care back offices working with the NHAIS system, the PDS NBO is responsible for resolving incidents with a patient's demographic record in the NHS Care Records Service. These include:

- **duplicates** - where two records are present for the same patient
- **confusions** - where two patients are using the same record, also known as mis-associated records
- **changes of identity** - for example,

---

[6] http://www.connectingforhealth.nhs.uk/nhsnumber

[7] http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/nn4b

adoptions or gender reassignment

- **de-registrations from the NHS** - due to a patient request, or exit to the MoD or emigration from the UK
- **resolution of unmatched civil registrations** - births and deaths.

The PDS NBO now has the necessary tools to amend and update incorrect data items on the PDS.

All PDS data queries should be raised via the user's Local Service Desk, for forwarding to the PDS NBO. This will prevent duplication of incident reports, allow the PDS NBO to investigate the incident and, if necessary, update the PDS in the following situations:

- **Duplicate records** - the PDS NBO will invalidate one record, leaving the patient with a single unique NHS Number. The PDS NBO will co-ordinate the investigation of the duplicate records (as it may affect multiple locations) and will be responsible for communication of the final resolution decision.
- **Confusion records** (also known as mis-associated records) - should be reported to the PDS NBO as a matter of urgency via the local helpdesk.
- **Incorrect GP details** (i.e. an incorrect registration between a GP Practice and a patient).
- **Amending incorrect data items** - may arise from systems that are Choose and Book compliant but not fully integrated into the NHS Care Records Service.
- **Undeceasing a patient record**, where this has been set in error.
- **Flagging a patient's demographic record to restrict access** - further advice on managing this is available on the Demographics pages of the NHS CFH[8] website. However, in the particular situation where a patient has requested that access to their PDS record be restricted (described as the record being 'flagged'), the procedures are outlined below.

'Flagging' a PDS record - some patients may feel that improved access to their individual contact details may place them at risk should NHS staff misuse the systems. Other people, such as those in adoption cases, do clearly require additional safeguards. NHS healthcare professionals should therefore understand the controls available to protect the demographic data of more vulnerable patients. The process for applying additional controls was formerly known

---

[8] Demographics pages of NHS CFH website (note nww access only) http://nww.connectingforhealth.nhs.uk/demographics/backoffice

as ‘stop-noting’ but is now referred to as ‘flagging a record’.

Whilst the ability to flag a patient record has been in place for a number of years, the historic process has not been well understood within the NHS. This is largely due to it being a back office function involving small numbers of patient records. There has also been little publicity due to its inherently sensitive nature.

NHS patients have no legal right to prevent demographic data being stored in the PDS and the Government has determined that this will be the authoritative source of NHS demographic information. The NHS cannot comply with requests for data not to be held in the PDS and it is required to hold demographic data about its patients to:

- satisfy legal requirements for registers of patients under the care of each GP practice
- ensure that each individual presenting for care is ordinarily resident in the UK and therefore eligible for free care
- ensure that information about one patient does not become confused with that of another patient
- contact patients when they need to attend check-ups etc.

Although demographic data must be held, there are cases where access to a patient’s details must be strictly controlled. Access to demographic records can be restricted in the following circumstances:

- anyone who feels that their demographic details should not be accessible by the NHS
- adoptions
- gender reassignment
- other situations where vulnerable patients request restricted access.

Further information about this is available on the NHS CFH website. These cases are managed by the PDS NBO using well-established links. There may be some cases where a request to have a record flagged is overridden, for example when there is a police investigation into a serious crime.

If a patient’s record is flagged the patient will be unable to benefit from any of the new national systems, including Choose and Book, GP2GP and the Electronic Prescription Service. Other national services such as cancer screening, GP registration and payments will not be affected. It also means that healthcare professionals will be unable to access the patient’s most up to date address and contact details held nationally. Even if a record is flagged the NHS will continue to hold demographic information on the patient.

There may be other reasons for flagging a record than those described above, for example where there is a concern about the accuracy of the data. The flag is applied to that patient's record only and remains on file should the patient move address. The current version of the PDS supports the following three reasons for flagging due to inaccurate data:

- **Invalid** – the flag indicates that an invalid NHS Number has been used or that a record is no longer in use (e.g. where two patient records have been merged and one is no longer used). The healthcare professional will not be able to see any demographics information for the patient. Dependent upon the user's IT system, a message will be displayed to the user indicating that the record is not valid and that the user should search for the correct demographics record.
- **Business** - the flag indicates that the the PDS NBO believes that there is a possible data quality issue with the record, (e.g. a duplicate record). The healthcare professional will be able to see the patient's full demographic details. Dependent upon the user's IT system, a message will be displayed to the user indicating that there is a possible data quality issue and will ask the user to verify demographic details when the patient presents to the NHS.
- **Sensitive** - the flag indicates that the patient's record has had access restricted as it contains sensitive information (e.g. where the patient is subject to an adoption). Healthcare professionals will have restricted access to a patient's demographic details, for example their address and registered GP practice will not be provided. No other demographic details will be displayed; including the patient's registered or preferred pharmacy.

Patients falling within the categories listed above should be referred to the appropriate organisation, such as social services, which will ensure that the patient's medical record is dealt with appropriately.

For the small number of patients who approach healthcare professionals and request that their records are flagged, the process described below should be followed.

Healthcare professionals are not expected to make the final decision about whether a patient's record is flagged (this is the patient's responsibility), however, healthcare professionals are expected to inform and guide patients through the decision making process and to stress that flagging records should not be undertaken lightly. The process for this is to:

- Advise and reassure the patient of the safeguards in place around the demographic information held in the PDS.
- Advise the patient of the potential clinical impact of their decision.
- If the patient understands and consents to the clinical implications of this action, complete the form[10] and fax it to the PDS NBO on (01633) 652580. Alternatively the form may be emailed from an NHSmail account to gm.e.ons-hg.tline@nhs.net. Please note that as the request includes patient identifiable data it should not be sent using any other email system. NHSmail is certified for the secure transfer of this type of data.
- The form should be retained with the patient's medical records.
- The PDS NBO will set the sensitive flag as a matter of urgency and then confirm in writing with the GP once the process is complete.

Should a patient request that their sensitive flag be removed, there is a similar process to the one described above:

- Complete the form[11] and fax it to the PDS NBO on (01633) 652 580. Alternatively the form may be emailed from an NHSmail account to gm.e.ons-hg.tline@nhs.net. Please note that as the request includes patient identifiable data it should not be sent using any other email system. NHSmail is certified for the secure transfer of this type of data.
- The form should be retained with the patient's medical records.
- The PDS NBO will remove the sensitive flag as a matter of urgency and then confirm in writing with the GP once the process is complete.

---

[10] PDS 'flagged record' request form (note nww access only) http://nww.connectingforhealth.nhs.uk/demographics/backoffice/flag/set_sensitive_flag.doc

[11] PDS 'remove flagged record' request form (note nww access only) http://nww.connectingforhealth.nhs.uk/demographics/backoffice/flag/remove_sensitive_flag.doc

Appendix 1 - What information is held in the PDS?

NHS Number – the unique patient identifier.

Patient name – including any previous names, aliases and preferred name.

Date of birth – patient's date of birth.

Additional birth information – the delivery time and birth order for multiple births.

Date of death – the patient's date of death.

Death notification status – indicates a formal death certificate has been issued for the patient and the death has been registered.

Gender – administrative gender.

Address – includes main address, temporary addresses and correspondence addresses.

Alternative contacts – the patient's legal guardian, proxy, family or close contact.

Telecommunication contact details – telephone number, fax number and email address.

Preferred contact times – patient's preferred contact times.

Preferred contact method – the patient's preferred contact method, e.g. telephone contact by proxy, no telephone contact, sign language required in face to face contact or minicom.

Preferred written communication format – specialised patient contact requirements, e.g. print, Braille, audio tape.

Preferred language – patient's preferred language for communication.

Interpreter required – indicates patient's need for interpreter.

NHS Care Record consent to share status – indicates whether or not the patient has agreed to share their NHS Care Record.

Nominated dispensing contractors - the patients nominated dispensing contractor that could include a community pharmacy, dispensing appliance contractor and a dispensing doctor.

No NHAIS posting – indicates the patient is not registered with a GP.

Previous NHS contact indicator – indicates the patient confirms they have had previous NHS treatment. This allows the PDS NBO to check for a duplicate record.

Patient call-back consent status – indicates the patient is willing to be called-back from a Choose and Book call-centre.

Shared secret – an encrypted password used to validate a patient's identity when contacted from a Choose and Book call-centre.

Sensitive record indicator – indicates that either the record is not accessible to the PDS users or the content of the record is being reviewed to ensure the data is correct.

Primary care – the GP with whom the patient is registered.

Serial change number – the mechanism for synchronising local and national records.

HealthSpace status – indicates that the patient is registered to use HealthSpace.

Appendix 2 - Completing the GMS1 Form

Data Item	Format	Notes
NHS Number	10 Digit Number	Please do not use old-format numbers, made-up numbers, Scottish CHI Numbers or National Insurance numbers. The NHS Number for a new born child can normally be found on their discharge letter or FP58 form.
Surname		Check spellings carefully and ensure that the official name is used (not an alias, or preferred nickname).
Previous name		Please enter any previous surname (e.g. maiden name). If there is more than one previous surname enter the most recent and list others in the comments field.

Forenames		Enter full names when known. If unknown enter initials. Please ensure that the official name(s) are used (not an alias, nickname or shortened version).
Title	Mr, Mrs, Miss, Ms, Dr, Rev	Please seek guidance for other titles not in regular use.
Gender	Male / Female	Please do not use 'Indeterminate' – recording the correct gender is essential for the cancer screening programme.
Date of birth	DD / MM / YYYY	Please enter correct date of birth for patient, taking special care not to mix up when registering families. Do not make up a date of birth.
Place of birth	Town – if UK Country – if non-UK	Please enter the precise place of birth. Do not enter 'unknown' in this field, or make up a place of birth.
Home address		Please use full current address including postcode.
Previous address(es)		Please enter full previous address where patient was last registered with a GP including postcode. This is essential to facilitate transfer of medical records. Please do not enter unknown.
Previous GP		Name of GP practice registered with when living at the previous address.
Previous GP's address		Address of previous GP practice.

Date of Entry into the UK	DD / MM / YYYY Comments screen	For patients registering from abroad, it is essential to ascertain whether they are coming to the UK for the first time. If they are returning having previously been registered in the UK, please ascertain the original date of arrival and place of registration.
Ex-Service Personnel		Please provide service number and enlistment date.

Appendix 3 - Glossary of Terms

Detailed Care Records

Detailed care records are linked medical records holding clinical information which are held by the organisations that work together locally to provide patients with care. They contain more detail than Summary Care Records and are particularly useful where a patient's care is shared between different parts of the local NHS, such as their GP Practice and hospital.

More details - http://www.nhscarerecords.nhs.uk

Electronic health records

An electronic health record (EHR) refers to an individual patient's health record in digital format. Electronic health record systems co-ordinate the storage and retrieval of individual records with the aid of computers. EHRs are usually accessed on a computer, often over a network. It may be made up of electronic medical records (EMRs) from many locations and/or sources. A variety of types of healthcare-related information may be stored and accessed in this way.

GP Record

The local record held for the patient by a GP Practice. This is typically composed of a paper record (the Lloyd George file) and an electronic record stored on a GP system.

HealthSpace

HealthSpace is a secure NHS web service for people who live in England. HealthSpace provides people with a secure place on the internet where they can store their personal health information and record information relating to their health like height, weight, blood pressure, blood sugar levels and cholesterol levels. HealthSpace also has a calendar and address book facility and allows users to search a database of contact details for NHS organisations in England.

More details - http://www.healthspace.nhs.uk

NHS Care Record Service

The NHS in England is introducing the NHS Care Records Service (NHS CRS). This is to improve the safety and quality of patient care.

Over time, the NHS CRS will begin to provide healthcare staff with quicker access to reliable information about patients to help with their treatment, including in an emergency.

It is likely that most GPs and consultants already use a computer system to keep notes of appointments they have with patients, plus medicines prescribed, test results and details of any referrals to other health professionals. X-rays and scans are also increasingly held on computers rather than sheets of film.

The NHS Care Records Service will make caring for patients across organisational boundaries safer and more efficient. It will also give patients access to a record that covers their care across different organisations, such as the GP practice and the hospital.

The purpose of NHS CRS is to allow information about patients to be accessed more quickly, and gradually to phase out paper and film records which can be more difficult to access.

More details - http://www.nhscarerecords.nhs.uk

NHS Number

The NHS Number is fundamental to the National Programme for IT. It is the common unique identifier that makes it possible to share patient information across the whole of the NHS safely, efficiently and accurately. The NHS Number is the key to unlocking services such as the NHS Care Records Service, Choose and Book or the Electronic Prescription Service.

Both patients and NHS staff have a vital role in ensuring it is used throughout the National Health Service.

The NHS Number is used as the common identifier for patients across different NHS organisations. It is a unique 10 digit number assigned to every individual registered with the NHS in England, Wales and the Isle of Man. The first nine digits are the identifier, and the tenth is a check digit used to confirm the number's validity.

More details - http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber

Personal Demographics Service

The Personal Demographics Service (PDS) is the national electronic database of NHS patient demographic details and the central source of patient demographic information used within NHS Organisations.

The PDS enables a patient to be readily identified by healthcare professionals and associated, quickly and accurately, with their correct medical details. The PDS does not hold any clinical or sensitive data items such as ethnicity or religion

The PDS underpins the development of linked detailed electronic care records and a Summary Care Record for every registered NHS patient in England.

More details - http://www.connectingforhealth.nhs.uk/systemsandservices/demographics

Registration Authority

The NHS Care Records Service (NHS CRS) and related National Programme for IT (NPfIT) services like Choose and Book and the Electronic Prescription Service use a common approach to protect the security and confidentiality of every patient's personal and health care details. It is essential that everyone who will have access to patient information has been through the same rigorous identity checks.

The NHS has set out the principles that will govern how patient information is held in the NHS CRS and the way it is shared. These are outlined in the NHS Care Record Guarantee and will be reviewed at least every twelve months as the NHS Care Records Service develops.

Organisations that need to access patient information within the NHS Care Records Service and other National Programmes set up Registration Authorities to manage this process.

The Registration Authority is responsible for verifying the identity of health care professionals and workers who wish to register to use these services.

Once authorised, individuals are issued

an NHS CRS Smartcard by the Registration Authority. Individuals use their NHS CRS Smartcard and their Smartcard Passcode each time they log on.

More details - http://www.connectingforhealth.nhs.uk/systemsandservices/rasmartcards

Smartcards

NHS CRS Smartcards help control who accesses the NHS CRS and what level of access that they can have.

They are similar to a chip and PIN credit or debit card, but are more secure. A user's Smartcard is printed with their name, photograph and unique user identity number.

To register for a Smartcard, Registration Authorities are required to ask applicants for identification which satisfies the government recommended standard 'e-Gif Level 3', providing at least three forms of ID (photo and non-photo), including proof of address.

Individuals are granted access to patient information based on their work and level of involvement in patient care. This means that for example, a doctor's receptionist may only see the information needed to process an appointment, not the full clinical record.

Each time someone accesses a patient's record, it will be recorded and patients can formally request to see this information.

Staff will also continue to be bound by professional codes of conduct, local regulations, the Data Protection Act and the NHS Code of Confidentiality.

More details - http://www.connectingforhealth.nhs.uk/systemsandservices/rasmartcards

Summary Care Records

A Summary Care Record is a summary of a patient's key clinical health information that will be available to anyone treating the patient in the NHS across England. The Summary Care Record will have their medications, any allergies and any bad reactions to medicines. With the patient's permission, it will build over time to include their main health issues such as diabetes.

More details - http://www.nhscarerecords.nhs.uk

NHS Connecting for Health is the national organisation which is supporting your local NHS to introduce new computer systems and services. These will help us to deliver better, safer care for NHS patients. For more information about this, visit *www.connectingforhealth.nhs.uk*

Ref: 3955