Data Provision Notice

General Practice to Diabetic Retinopathy Screening (GP2DRS)

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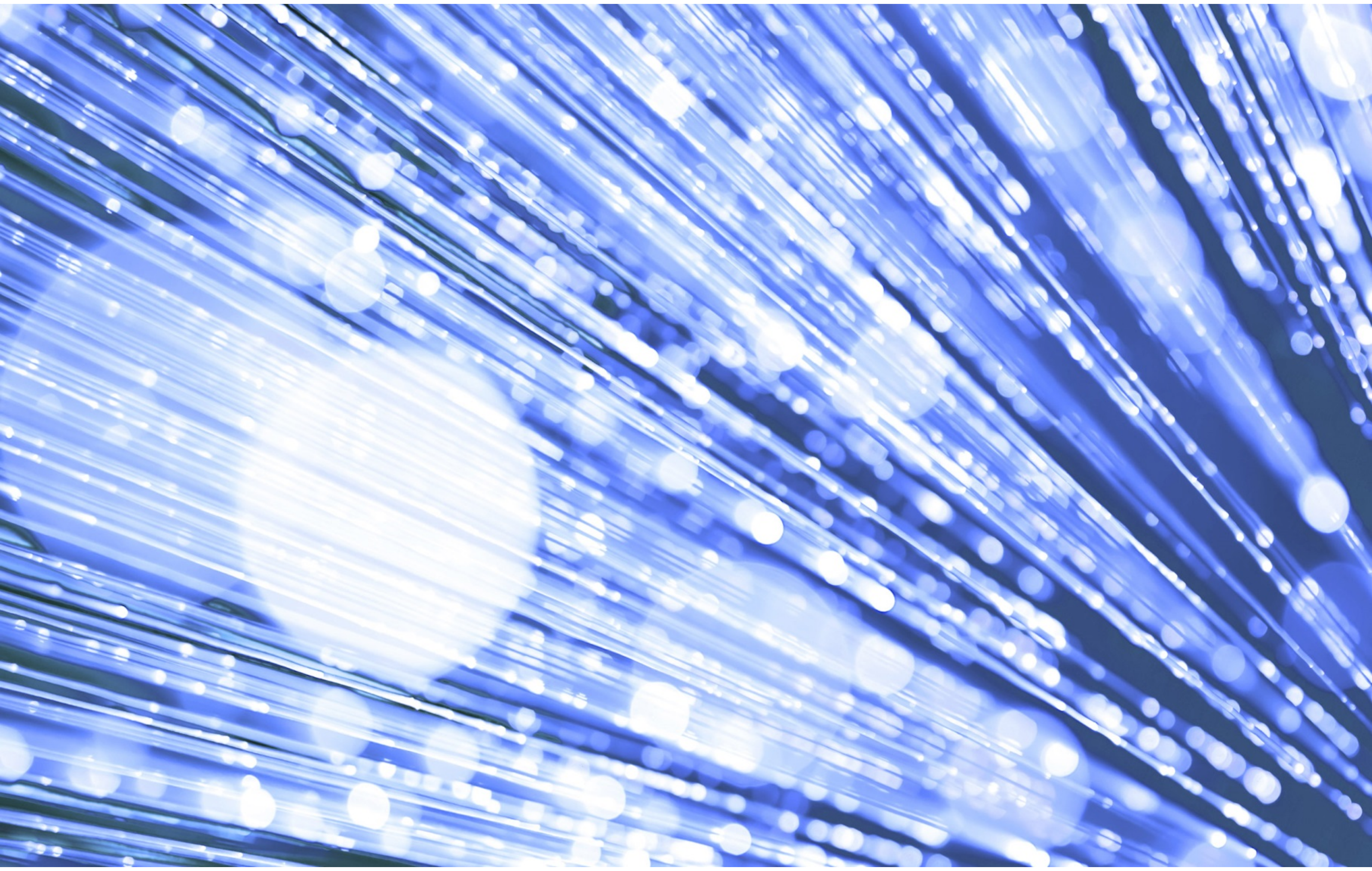
Version: 2.0
Published: 3 September 2021



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Background

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre, now known as NHS Digital and hereafter referred to by this name, statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice (**DPN**[1]), is required to support a direction from the Secretary of State for Health and Social Care to NHS Digital. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose of the collection

Diabetic retinopathy is one of the most common causes of blindness in the UK. Screening is the process which identifies people who appear healthy, but who may be at increased risk of a disease or condition. Evidence shows that early identification and treatment of diabetic eye disease could reduce sight loss. This requirement is being implemented by the UK National Screening Committee (UK NSC) on behalf of Public Health England (PHE).

PHE requested that NHS Digital establish this collection to improve the process for inviting patients to attend a screening appointment. General Practice to Diabetic Retinopathy Screening (GP2DRS) is a system which automates the sharing of patient information between general practices and local diabetic eye screening programmes to make the process easier by extracting the information directly from General Practice (GP) systems and removing the need for manual processing.

NHS Digital began extracting GP2DRS data in January 2015. Prior to NHS Digital receiving the direction from the Secretary of State for Health and Social Care, the legal basis for the collection was direct care.

Information regarding eligible patients is obtained from general practices using the General Practice Extraction Service (GPES) and is entirely reliant on correct information being recorded in GP systems. Once extracted, the data is uploaded into the GP2DRS database, designed by PHE, and enables screening programmes to view a central repository of extracted data and use it to identify and invite eligible patients for diabetic retinopathy screening. PHE does not routinely access the data itself for inviting patients for screening and the data is not published or shared outside of the GP2DRS programme.

The following provides more information about why the collection is necessary:

Diabetic eye screening: professional guidance

These national policy documents set out operational guidance for the NHS diabetic eye screening (DES) programme.
https://www.gov.uk/government/collections/diabetic-eye-screening-commission-and-provide

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[1] This DPN supersedes version 1.0 published in August 2018

Benefits of the collection

Benefits to patients:

- prompt referral to screening programme upon diagnosis
- prompt identification of changes in details, for example a change in address
- prompt identification of deceased patients
- clearer approach to patient consent to data transfer
- prompt communication from Screening Programmes.

Benefits to Screening Programmes:

- identification of eligible patients
- automatic rather than manual data collation
- improved accuracy of patient register
- validation of patients list
- timely notification of deceased patients or patients who have left the screening programme area
- improved alignment of data between general practice and the screening programme
- reduce administration overhead.

Legal basis for the collection, analysis, publication and dissemination

Collection and Analysis

NHS Digital has a legal obligation to collect patient information for GP2DRS as it has been directed by Secretary of State for Health and Social Care under sections 254 and 304 of the Health and Social Care Act 2012; to establish and operate a system for the collection and analysis of the information specified for this service. A copy of the NHS Diabetic Eye Screening Programme (Eligible Population Identification) Direction is published here: https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/public-health-england-directions/direction-for-the-general-practice-to-diabetic-retinopathy-screening-gp2drs.

Appendix A provides a link to the Specification where details of each data item to be extracted can be found. (The ‘missing patients’ data extract is currently paused.)

Under section 254 of the Act, NHS Digital is directed to:

- Collect from all General Practices in England information as specified in Annex 1 of the above Direction on all patients eligible to be invited for diabetic eye screening.

- Collect this information on a monthly basis.

In line with section 259(5) of the Act, all organisations in scope, in England, must comply with the requirement and provide information to NHS Digital in the form, manner and period specified in this DPN.

This Notice is issued in accordance with the procedure published as part of NHS Digital duty under section 259(8) of the 2012 Act.

National Data Opt-outs

Patients can choose to opt-out of sharing their data for various purposes:

- National Data Opt-Out – this allows patients to choose whether their confidential patient information is used for *research and planning*. (It was previously known as a 'Type 2 Opt-Out, prior to 11 October 2018.)
- Type 1 Opt-Out – this allows patients to tell their GP if they do not want their confidential patient information held in their GP medical record to be used for purposes *other than their individual care*.

The transfer of patient information via GP2DRS is not for research and planning; it is for the patient's own care. This means that neither of these opt-outs apply to GP2DRS. A patient is not excluded from GP2DRS by virtue of having either of these opt-outs on their medical record.

Dissemination

NHS Digital is directed in accordance with section 261(3) and 262(3)(a) of the Act to disseminate the information obtained by complying with the above Direction and specified in Appendix A to PHE, which PHE will make available to local screening programmes for the purpose of inviting eligible patients for diabetic eye screening.

There is a Data Sharing Agreement with PHE in place. Data is not and cannot be disseminated to other organisations.

Publication

NHS Digital is directed in accordance with section 260(1) and (2)(d) of the Act not to publish the information obtained by complying with this Direction.

Transparency

NHS Digital is collecting personal data from general practices to facilitate the GP2DRS data collection. General practices have a legal duty to be transparent and to provide patients with transparency information under the UK General Data Protection Regulation (UK GDPR) about the data they are sharing with NHS Digital.

NHS Digital has issued a Transparency Notice for this data collection. This Transparency Notice ensures that NHS Digital meets its legal duty in line with the UK GDPR and the Data Protection Act 2018 and supports general practices in meeting their legal duty in line with the UK GDPR and the Data Protection Act 2018.

General practices need to update their own Transparency Notices on their websites to include details of this collection. It is intended that general practices should be able to link to the information included in the NHS Digital Transparency Notice to enable them to perform their legal duty in providing adequate fair processing information to their patients. To meet fair processing responsibilities for this data collection, general practices are required to:

- inform their patients how their personal data will be used (including what type of data will be used) and for what purpose(s) their personal data will be used

• reassure their patients that their personal data will remain safe and confidential and will be used only for its intended purpose.

Dissemination of data is limited to PHE. PHE are required under UK GDPR to update their Transparency Notice.

Persons consulted

NHS Digital has, as required under section 258 of the 2012 consulted with the following organisations:

The Data Coordination Board (DCB)[2] –The DCB has been established as part of a system-wide information and technology governance model, as a sub board of the Digital Delivery Board (DDB). The DCB acts with delegated authority from the DDB and directly from the Secretary of State as the main governance route through which all data collections and standards requirements will be agreed, and priorities assigned.

The DCB has a broad role in engaging system partners to support NHS Digital in its statutory function to reduce the burden of data collection. The DCB operating remit covers all Arm's Length Bodies (ALBs) and Adult Social Care and has structured its membership to support this remit.

The GP2DRS data collection was previously subject to the legal basis being direct care and NHS Digital consulted with the following organisations:

- Public Health England
- NHS Digital's Independent Advisory Group (IAG)

This requirement is being implemented by the UK National Screening Committee (UK NSC) on behalf of Public Health England (PHE).

NHS Digital's Independent Advisory Group (IAG) for the General Practice Extraction Service (GPES) recommended that the GP2DRS information collection should proceed:

Link to Information Governance Assessment

http://webarchive.nationalarchives.gov.uk/20160921184821/http://digital.nhs.uk/media/12606/Diabetic-Retinopathy-Screening---Information-Governance-Assessment/pdf/GP2DRS_-_HSCIC_Information_Governance_Assessment_-_August_2013_(NIC-154590-YG6QH).pdf

Link to 2013 GPES IAG meeting minutes

http://webarchive.nationalarchives.gov.uk/20160923031228/http://www.digital.nhs.uk/article/4958/2013-GPES-IAG-meeting-minutes

Approval of this collection was recommended by NHS Digital's Independent Group Advising on the Release of Data (IGARD).

Scope of the collection

Under section 259(1)(a) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS Digital duty under section 259(8) on the following persons:

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[2] DCB is superseded by the Data Alliance Partnership Board (DAPB) - established in November 2020 as part of a system-wide information and technology governance model. The DAPB acts with delegated authority from the Secretary of State as the main governance route through which all data collections and standards requirements are agreed and priorities assigned.

- all general practices in England

The National Data Opt-Out will not apply to the submission of data to NHS Digital for this collection as the DPN is a legal requirement with which the participating organisations must comply.

Under section 259(5) of the Health and Social Care Act 2012 the organisation types specified in the above Scope must comply with the Form, Manner and Period requirements below:

Form of the collection

The GPES data extraction identifies all patients that (as at the query execution start date) are registered with a general practice, are 12 years of age or older, have a current diagnosis of diabetes and have not withheld consent for the extraction of demographic information. Appendix A provides a link to the Specification where details of each data item to be extracted can be found.

The GPES data extraction will also look to extract certain clinical information about the patients identified above but only where explicit consent is recorded in a patient's record and will also identify patients who were in the cohort of diabetes patient in the last extract but who are no longer in the cohort of diabetes patients.

For each extract, PHE receive one Customer Request Output (CRO) file per GP practice each month. The CRO files are uploaded into the GP2DRS database.

In addition to the CRO file that PHE receives, a separate file is created which contains two data items - NHS Number and registered practice identifier - and the practices at which those patients were registered. This is temporarily stored in the NHS Digital Data Management Environment (DME). This patient cohort list is used as the basis for a further GPES extraction as a product of comparing patient records extracted in the previous month with patient records identified in the current month's extract.

The Data extracted incudes patient level information. This information is necessary to invite people to attend screening.

Link to Customer Requirement Summary

http://webarchive.nationalarchives.gov.uk/20160921184818/http://digital.nhs.uk/media/12604/Diabetic-Retinopathy-Screening---Customer-Requirement-Summary/pdf/GP2DRS_-_Customer_Requirement_Summary_-_August_2013_(NIC-154590-YG6QH).pdf

Manner of the collection

General practices that have accepted the Calculating Quality Reporting Service (CQRS) offer to participate previously will have this participation rolled over each year and do not need to do anything to remain participating in future GP2DRS data collections.

Remaining general practices will be sent an invitation to participate via the Calculating Quality Reporting Service (CQRS). This invitation must be accepted as there is a Direction in place for this data collection and it is a legal requirement for general practices to provide this data under section 259(1)(a). All general practices are therefore mandated to comply with this invitation and approve the collection.

Period of the collection

This collection is an established ongoing existing data collection and requires that data extracts take place on a monthly basis.

The start date for each extract will remain the same for each extraction and the reporting period end date is always the last day of each month.

The first extract took place in January 2015.

Data will be collected via GPES (see Appendix A: Specification), which will involve the appropriate data being collected from general practices' clinical IT systems. The NHS Digital GP Collections webpage[3] provides further information on GPES.

Data quality

This collection will only involve data being collected from general practices' clinical IT systems; other systems maintained by general practices are out of scope.

GPES provides a data certification service, which tests whether the technical specification for a data collection is correctly defined. The general practice system suppliers must pass certification before the data are collected.

Data certification is used to reduce the risk of data quality issues, yet some issues may persist following certification. This is because the data collections will only be as good as the data inputs. GPES also cannot give assurances that the returned data fully meet the key data quality principles of accuracy, completeness and timeliness.

Burden of the collection

Steps taken by NHS Digital to minimise the burden of collection

In discharging its statutory duty to seek to minimise the burden it imposes on others NHS Digital has:

- sought to minimise the burden on general practices by using existing data extract technology, rather than requesting information in another format which may be more burdensome to process.

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the Health and Social Care Act 2012, NHS Digital has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership Board (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

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[3] https://digital.nhs.uk/services/general-practice-gp-collections

Detailed burden assessment findings

There is minimal burden on general practices as the collection is automatically extracted by the general practice system suppliers. Information required is routinely collected and recorded in general practice systems as part of the ongoing interaction between GPs and their patients.

Assessed costs

The associated burden of the data collection is:

Burden on providers	£50.7k	Based upon circa 6,700 General Practices. 4 minutes per General Practice manager. .
Set up costs for the data collection	Nil	This is an ongoing extract so there are no set up costs involved.
Other costs of the data collection	£113.4k	This covers the expected annual general practice system supplier costs as well as the GPES running costs.
Total burden	**£164.10**	**Overall, total burden of GPES collection.**

Appendix A: Specification

SNOMED Development:

Following the introduction of SNOMED CT, the data extract requirement needed to be updated to ensure appropriate codes are identified, to ensure that business rules are updated and to ensure flexibility is built into the extraction through the use of 'Ref Sets'. Where SNOMED CT code releases are made throughout the year, NHS Digital will highlight any impact of those code releases and will propose specific changes to the 'Ref Sets' (for PHE to consider) to ensure the objectives of the data extract continue to be met. NHS Digital will maintain these 'Ref Sets' in line with feedback provided by PHE. The SNOMED version of the GP2DRS extract will be the primary data collection going forwards, subject to PHE completing its quality assurance review of this extract. Once this has been achieved, the previous READ v2/CTV3 version will be retired.

The patient/record data that will be included in the GP2DRS READv2/CTV3 version 2 / SNOMED CT version 3, or the latest amended version as agreed by PHE, may be found on the Business Rules page on NHS Digital's website:

READv2/CTV3 business rules:

https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns/general-practice-to-diabetic-retinopathy-screening-gp2drs-data-provision-notice

SNOMED CT business rules:

GP2DRS (Diabetic eye screening programme) - NHS Digital

List of data items to be transferred from NHS Digital to Public Health England for dissemination to the local NHS diabetic eye screening programmes.

Full cohort

Provides the following details for eligible patients, as at the query execution start date. 'Eligible patients' being any patient registered with a GP practice in England who is aged 12 years or over, with a diagnosis of diabetes and who is not withholding consent to the transfer of their demographic information for diabetic eye screening.

Data item name	Data item description
PATIENT.REFERENCE	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process. This is a unique identifier which is used to identify individual patients. This unique identifier may be used to associate information extracted from the same practice about the same patient on different occasions. This will also be used as part of cohort identification when matching patient information within GP2DRS database.
PATIENT.DATE_OF_BIRTH	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process. This will facilitate accurate identification of patient by care provider and exclusion from cohort where under 12.
PATIENT.SEX	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process (data

Data item name	Data item description
	management, service delivery). This will facilitate accurate identification of patient.
PATIENT.POSTCODE	This is the patient’s postcode of current address.
PATIENT.GP	This is the GMP number of the patient’s current registered doctor. To co-ordinate the ongoing care process (data management, service delivery). This will also be used by some screening programme systems to facilitate the link to general practice.
PATIENT.ACTIVE	This item is to extract the current registration status of patients at a practice. This item is required in order to identify those patients that should be invited for diabetic retinopathy screening. It is also to be used to identify those patients whose registration status has changed. Often as a consequence of this, the patient will have also left the screening programme cohort, but this is not true in all cases, for example when a patient leaves a practice they do not leave the screening programme cohort until they re-register at another practice.
PATIENT.REGISTERED-DATE	Associated with PATIENT.ACTIVE data item to determine when a patient registered with a general practice.
PATIENT.REMOVED-DATE	Associated with ACTIVE data item to determine when a patient's general practice registration ends.
PATIENT.DATE-OF-DEATH	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process (data management, service delivery). It will also be used to inform screening programmes that no further care/correspondence should be planned/communicated.
PATIENT.PCG	This is to identify the responsible Primary Care Group (PCG)/Clinical Care Group (CCG) for a patient. Provides link to other GP2DRS PCG/Clinical Commissioning Groups (CCG) data to identify the healthcare body responsible for providing diabetes services locally.
PATIENT.PRACTICE	This is the current practice code of where a patient is registered. This will provide a link to other GP2DRS GP data that includes general practice address and contact details. It is required to identify the general practice at which a patient is registered and to facilitate the communication of screenings results letters and to co-ordinate the ongoing care process.
PATIENT.SURNAME	This is to extract the surname of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.FORENAME	This is to extract the forename of the patient for communications purposes including posting of invitation to

Data item name	Data item description
	screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.TITLE	This is to extract the title of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.NHS-NUMBER	This is the patient’s NHS Number and is one of the data items used to identify the person receiving healthcare and to inform the ongoing care process. It will also be used to identify patients who have exited since last extract (e.g. no longer diabetic and age corrected as well as deceased and de-registered).
PATIENT.ADDRESS	This is to extract the full address of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching. This item is required in case data item below is missing from a patient record.
PATIENT.ADDRESS-1	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-2	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-3	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-4	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-5	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.PRACT-NUMBER	This is the practice number that is assigned to a patient within a practice and is one of the data items used to identify the person receiving healthcare and to inform the ongoing care process.
PATIENT.ETHNIC	This is to extract the ethnicity of a patient which allows for analysis of ethnicity. It will also be used to evaluate patient experience. For example, the rate of development of diabetic retinopathy differs between ethnic groups, those in

Data item name	Data item description
	some groups will be at elevated risk, both at higher risk of having diabetic retinopathy when they are first screened and to progress to sight threatening diabetic retinopathy (STDR) within a few years of diagnosis of diabetes.
PATIENT.FIRST-LANGUAGE	This is to identify the first language of a patient which is to be used as part of the patient's ongoing care process.
JOURNALS.DATE	Date to which the coded journal item applies. This is not the RECORD_DATE which records when the item was coded. For example, if a patient attended screening on ‘2014-03-05’ and the code was entered into the system on ‘2014-06-30’ this DATE will be ‘2014-03-05’.
JOURNALS.CODE	The clinical code indicating the nature of the characteristic, event or intervention as per the clinical code tables.
JOURNALS.TIME	Time at which the journal item applied.

For further information

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