

FAO: Joanne Andrews
North East Kent Coroners
Cantium House
Country Hall
Sandling Road
Maidstone
Kent
ME14 1XD

By Email Only: kentandmedwaycoroners@kent.gov.uk

Your ref: [REDACTED]

Our ref: [REDACTED]

4 February 2021

Dear Ms Andrews

Inquest into the death of Mr Ronald Richard Tilley

I am writing in response to the Regulation 28 report received from HM Coroner dated 4 December 2020. This follows the death of Ronald Richard Tilley, who sadly died on 23 October 2019. This was followed by an investigation and inquest which concluded on 29 October 2020. I would like to express my sincerest condolences to Mr Tilley's family. NHS Digital provided written statements in advance of the inquest, but did not attend the inquest.

NHS Digital is a non-departmental public body created by the Health and Social Care Act 2012 and is the national information and technology partner for the health and care system. We use technology to support the NHS and social care.

NHS Digital operates and maintains the Personal Demographics Service ('PDS') under the Spine Services No.2 Directions issued by the Secretary of State for Health and Social Care to maintain a register of NHS patients in England. PDS is the national electronic database of NHS patient details such as name, address, date of birth and NHS Number (known as demographic data). It also records the primary care registration (i.e. the GP practice with which the patient is registered for general medical services¹) held by each registered patient and as notified through other NHS systems. PDS enables NHS and partner organisations delivering health and care services to

¹ General medical services are a range of essential services which general practitioners are required to provide to meet the needs of its patients as covered by their contract with NHS England.

collect, record, access and share information about patients. This is so that they can be accurately identified and that the correct health and care records can be retrieved from local and national systems. Additionally, PDS supports national communication with patients in relation to their health and care needs.

In the initial statements from [REDACTED], the following information was provided:

- who updated Mr Tilley's GP practice code on PDS;
- when Mr Tilley's GP practice code was updated on PDS;
- the functions of the NHS Spine; and
- security governance of, including access to, NHS Spine.

NHS Digital was unable to explain why the GP practice code at Mr Tilley's record on PDS had been updated, as that information is not held on our systems.

In HM Coroner's Regulation 28 report of 4 December 2020, the matter of concern was that when a record on the PDS is updated or amended, there is no notification sent to the existing GP noted on the system. As this inquest concerned the change to Mr Tilley's GP practice code on PDS, I shall focus my response on the management of this data. I will provide information on the business processes that would ordinarily lead to a GP practice code being updated on PDS, the information that is available to GP practices when accessing PDS, and statistical data with respect to PDS data quality.

The primary care registration management process within the NHS in England is managed through a range of different systems which, when operated correctly, ensure a patient's GP registration transfers from one GP practice to another. The successful registration of a patient with a new GP practice includes the appropriate generation of notifications to the different systems involved in the process.

Registration for general medical services (GMS)

A patient wishing to register with a GP for general medical services is normally required to complete the Family Doctor Services Registration form known as GMS1. This includes information to identify the patient and, where possible, the GP practice that the patient is leaving. Using the information provided, the new GP practice will register the patient on their clinical system.

At this stage of the registration process there are two paths available. Either:

1. The GP clinical system updates PDS directly with the new GP code and notifies National Health Application and Infrastructure Service² ('NHAIS') via the GP Links Registration message; or

² NHAIS is an NHS Digital service providing a suite of software implemented across primary care which manages services, patient registration, and demographic details.

2. The GP clinical system does not update PDS directly and notifies NHAIS via the GP Links Registration message.

In either case, Primary Care Support England ('**PCSE**'), who have responsibility for managing primary care registration on behalf of NHS England, will validate and complete the registration by updating PDS with the GP practice code, depending on the chosen pathway, and apply a geographic administrative indicator known as an NHAIS cipher. In completing this action, a series of notifications is triggered from PDS to inform the old GP practice of the transfer and deduct the patient from the practice's patient list and, separately, to initiate the transfer of the patient's paper medical record envelope, which is often referred to as "the Lloyd George".

In cases where the GP practice updates PDS directly (option 1 above), and the patient is transferring from another practice, this update will trigger the GP2GP process which allows the patient's electronic health record to be transferred directly between the old and new GP practice.

Therefore, in the event of the GMS registration being changed the old GP practice is notified of this.

Registration for 'Other' services

It is common for a patient to receive services from a GP practice other than the one which holds their GMS registration. In such cases, the practice providing these other services will register the patient on their clinical system for 'Other' services³.

A registration for 'Other' services will not update the GP practice code on PDS and therefore, will not trigger the GP2GP interaction. Nor will it generate a GP Links registration message to NHAIS. This 'Other' registration is held only on the local clinical system.

GP practice interaction with PDS

GP clinical system interaction with PDS is dependent on the individual user being logged on using their smartcard. This enables them to trace and update PDS patient records in line with their designated access rights.

It is standard practice in care settings, including primary care, to routinely check a patient's demographic data with them at each new encounter. This action should include interaction with PDS to ensure the most up to date information about the patient is available to them and other users with a legitimate relationship with the patient.

When a patient record is retrieved (traced) from PDS, the clinical system presents, on a split screen, the patient demographic data that is held locally against the information

³ Other services are provided by general practitioners in addition to those provided as general medical services, examples include contraceptive services, vaccines and immunisations, minor surgery.

on the PDS record. This allows the user at the GP practice to compare the data, see any differences and take appropriate action to synchronise systems, thus keeping them in-line with each other.

Neither the split screen nor any other part of this interaction will identify the GP practice code that is held on the PDS record. The logic around this is that GMS registration is managed through other means (GP Links Registration messages and NHAIS) and, in the absence of such notifications as described above, the legitimate relationship with the patient does not need to be reaffirmed during this interaction.

A user can still update their clinical system independently of PDS if they are not using their smartcard. In such circumstances, the update will be available only on the local clinical system.

Circumstances around Mr Tilley's GP update

It has been established that Mr Tilley was receiving 'Other' services from Bethesda Medical Centre and that there was a requirement for him to be recorded on their clinical system. Correct process would have seen him registered for 'Other' services as outlined above. This action would, correctly, not have generated any update to PDS.

Audit logs available to NHS Digital have been checked and there is no evidence of a GP Links Registration message from Bethesda to NHAIS. This indicates that Bethesda did not attempt to undertake a GMS registration for Mr Tilley.

In the course of investigating the background to this case we also contacted PCSE who confirmed that Bethesda Medical Centre had informed them that Mr Tilley was seen at their anticoagulant clinic regularly (since 2009, but particularly between 2015 and 2016). PCSE also advised that they did not receive any notification that Bethesda Medical Centre were to be the GMS provider.

GP Registration mismatch occurrence

It has been shown through this inquest that it is possible for a clinical system to update the GP practice code outside either the GMS or 'Other' services registration process. As far as can be determined, Bethesda appears to have acted outside of standard procedures (as outlined above).

There are around 60 million patients registered for primary care in England. Between April 2018 and December 2020 there were almost 16 million patient registration transfers between GPs. Allowing for business-as-usual differences where a new registration has been recorded but not yet validated in line with processes already described, it is unusual for there to be a mismatch between the GP practice code held on PDS and that recorded on the GP clinical systems across England. Recent analysis undertaken on this metric has shown the level of mismatch to be less than 1% of the total registered population, which is illustrative of the strength of the data quality across the system. This also demonstrates that the business processes and systems in place



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to manage patient primary care registration in England are well established, robust and effective in safeguarding patient care.

In cases where there may be a problem with the system flows, especially if associated with a patient death, I would expect these to come to our attention. Since the inception of the NHS Spine over 10 years ago and the introduction of current data flows, I have not been aware of another case with such an outcome. A low level of GP practice code mismatch does exist within the system, as outlined above. However, the correct application of business process allied with good technology enables similar cases affecting active patients to be identified and corrected through the national data quality management service at NHS Digital.

Whilst statistics may reflect positively on the system as a whole, I recognise that the key element of a quality service is the experience of individual patients and NHS Digital will take steps within its power to further reduce the risk of such untoward events. A programme of work is running which is in the process of rationalising and streamlining the systems and data flows in the management of primary care registration. The circumstances surrounding Mr Tilley's death will be brought to the attention of this programme so that improvements may be considered through appropriate consultation with system users and stakeholders.

If HM Coroner requires any further clarification in relation to any point, please do not hesitate to contact us and we can assist further.

Yours sincerely,


Service Manager

Personal Demographics Service National Back Office

NHS Digital