

Out of Hours

How not to contact the dead

Failure to correctly determine which of your research participants have died before you contact them is distressing both for the family and the researcher involved. For this reason it has become recognised practice in the UK to ascertain vital status prior to any telephone or postal correspondence. As a primary care physician relatively new to research I was surprised to learn that despite the necessity of the task, there is currently no consensus on the best way for a researcher to find out whether someone is dead or alive.

Accessing the death certificate from the Medical Research Information Service (MRIS) is one means of following up the vital status of a participant. It is an attractive option since it has the advantage of also providing the date and cause(s) of death.¹ This process is ideal in carrying out long-term follow-up. However, since information from MRIS arrives periodically there is a window of uncertainty within which the participant may have died without researcher notification. This lag between actual death and recorded death may be even more considerable in cases where patients have been subject to an inquest. This may lead to an unacceptably high risk of vital status error in many research studies.

Instead the research team often decides to contact the participant's GP to retrieve more up-to-date information. Unfortunately this process can be rather tedious. Pursuing the GP is labour intensive and costly both in terms of administration as well as reimbursement. With budgets becoming ever more scrutinised and academics more conscious of avoiding adverse events, one way researchers have attempted to circumvent this process has been to shift the onus of responsibility on the GP.

Asking the GP to contact the research team when a patient dies has its own problems. Importantly this process is more liable to error. The GP may simply forget that a particular patient has been recruited to a particular study (often a number of months or even years previously) or have patients in so many different studies that it is hard to keep track of them. This lack of organisation may seem rather antiquated to the researcher versed in project management, but it is easy to forget that

some GPs will have little interest or limited experience in 'academia'. Developing a local system to monitor and report back when participants have died to individual research teams is not straightforward and either takes GPs away from their usual clinical duties or utilises their administrative time/staff. This, in addition to not receiving any financial recompense or research recognition, means the GP has no incentive to respond to vital status requests beyond what they see as their duty as a doctor.

There is an alternative. The Personal Demographics Service (PDS) is the 'master source' for basic demographic information on every patient in the NHS.² It is currently used for systems and services such as Choose and Book and the Electronic Prescription Service. Of note, it includes information on patient address, current GP practice, and date of death (if applicable). Access to the PDS is limited to individuals with a NHS smartcard issued by Information Governance staff from the local registration authority (RA) once the identity of the user has been verified. Users are given a 'role profile' that specifies which activities are permitted on the PDS. Information should only be accessed by users with a genuine need to know or when patients have consented for their information to be viewed. An audit of which patient records are retrieved by particular users is automatically created to monitor appropriate use.

The PDS should not be confused with the summary care record (SCR). Whereas the PDS contains demographic information, the SCR contains clinical information such as patient allergies and medication.³ Critically, NHS patients cannot opt-out of the PDS unlike the SCR, although vulnerable patients can request their record be flagged to prevent potentially sensitive data being visible to users. A database such as the PDS which has the demographic data of all NHS patients could be potentially very useful for researchers but reignites issues surrounding the availability and electronic transfer of patient data. Indeed, there remain many misconceptions about what patient data are currently shared and available to users with an NHS smartcard.⁴ For this reason it would be wise to consent patients about the use of the PDS for research purposes when enrolling them to studies.

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The Care Record Guarantee discusses the use of paper or electronic medical records to help with research when patients have consented for their use.⁵ The PDS provides an opportunity for researchers to quickly gather basic demographic information about their consented research participants without having to burden GPs. By removing this administrative step it provides a more accurate and efficient means of following up NHS registered patients.

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