What added value would come from further data collection for a UK register of fatal anaphylaxis?

The register holds complete data for 1992—2000, complete but in many cases unconfirmed data for 2000—2005 and incomplete data from 2005—2012 comprising cases studied in great detail immediately following death. Analysis of the data so far has shed light on the basic epidemiology of fatal anaphylaxis (age, sex, race, geographical distribution; trigger agents and circumstances of fatal reactions). It has demonstrated general principles of why reactions were fatal and why attempts at rescue failed. Many issues remain unresolved that need further data collection and analysis:

1. Key to successful rescue from anaphylaxis is an understanding of the mechanisms by which they become lethal. What exactly is happening when? Careful evidence collection from hospital records and other witnesses can help this, for example with analysis of events in “biphasic anaphylaxis”. Our unpublished analysis of multiple fatal reactions suggests that anaphylaxis comprises multiple processes, each with its own time course. Successful rescue from the peak of an early process may be followed by death from the peak of a later one. More observations are needed to complete this analysis, which will be crucial to improve patients’ chance of survival.

2. Evaluation of reasons for rescue failure by first responders. Suboptimal paramedic training is known to be a major factor in failed rescue from anaphylaxis. This is not just a UK problem: the recent analysis of paramedic knowledge of anaphylaxis in the USA seems wholly consistent with fatal anaphylaxis cases in the UK. Each new case has provided new evidence and reinforced the accumulated evidence for issues demanding improved paramedic training in the UK.

3. Evaluation of benefits from adrenaline auto-injector carriage and exploration of reasons why provision of pens has failed to prevent sting and food allergy deaths. Since the register started in 1992, pen carriage in the UK has increased from <10 to >300,000, but the carriage by those dying from anaphylaxis increased from 1 in 4 to 5 in 8 food allergy deaths. A variety of reasons why pens have failed to rescue patients has emerged but on-going case collection is needed as part of an outcomes audit to monitor effectiveness of strategy changes in pen prescription.

4. Time trends: so far the register indicates that the rate of fatal anaphylaxis has remained constant. Recent data from other sources such as analysis of anaphylaxis treated in critical care suggest there has been a year-on-year increase in fatalities. Accurate comprehensive data on time trends of death from anaphylaxis will be useful for health economic analysis of the condition. While we have been ahead in Europe in collecting, analysing and publishing these data, other centres are now beginning to look at fatality data more systematically. We need to continue collecting UK data to ensure comparisons of trends are synchronous across Europe in our coordination of findings with the French, German and other networks with whom we are already working closely.

5. Novel causes of fatal reactions. New causes discovered so far include chlorhexidine and fungal protein used as meat substitute. Many cases have unconfirmed triggers that are likely to be clarified by detailed studies of further cases. For example, a significant proportion of fatal “contrast media” reactions may prove to have a hidden, non-contrast-medium cause such as chlorhexidine, as has now been established for one such death.
Further analysis of reasons underlying avoidance failure. Because rescue from anaphylaxis poses some unresolvable issues, avoidance of the trigger is clearly the better strategy. Data from fatalities is necessary to complete the findings of studies of avoidance failure in non-fatal reactions.

Continuing close cooperation with HM Coroners to provide dedicated expert analysis of the cause of death in cases of suspected fatal anaphylaxis. Coroners have advised us that they are thankful to know of the specialist interest in fatal anaphylaxis linked to the register. They have been able to conduct more thorough investigations and answer more questions for the families which in turn helps the families to come to terms with the death, and with greater confidence to act through the use of Rule 43 to prevent similar deaths and ‘near misses’. This collaboration has provided some of the best, most detailed data for the register.

Continuing provision of reports for medicolegal teams such as the Medical Defence Union or Criminal Prosecution Service. Again, as with reports for HM Coroners, these investigations provide access to medical and social records at the deepest level and have built-in quality assurance with the opposition exploring every aspect of our interpretation of the data with a view to disproving it.

There are many aspects of fatal anaphylaxis that remain unexplained and further data collection seems certain to be helpful. One example is “idiopathic anaphylaxis” where failure to determine the cause reflects our poor understanding of the relationship between trigger factors and anaphylactic reactions.

Throughout its 20 years the register has informed us in an advisory role to
a) Food Standards agency: assessment of allergen dose and presentation in fatal reactions, reasons for avoidance failure and so on are all issues of interest to the FSA and further data collection is certain to reveal new patterns to inform future guidelines and legislation.

b) To management guidelines development groups such as Resuscitation Council UK. Each new death gives further information for future improvement of management guidelines.

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Quotes from Dr Pumphrey
I think the sessional rate will fall to one per week once the backlog has been sorted -- and I think that should only take a year or so. Also -- I will help to get it all going and help in sorting out the data retrieved by the searches -- of course free of charge -- so the long-term annual rate should be limited to:

a) ONS search -- ?£200 pa
b) p/t "clerical" assistance (but much more than just clerical if it's Hazel Gowland doing it) rate to be negotiated
c) one consultant session per week (possibly 3 consultant sessions per month) I imagine that trainees may become involved in helping -- the data carry strong lessons for allergy management. If things go on as they are at present, CMFT will make no charge for the IT costs. For the output, this really is a very economical project.