

Gathering public views on new arrangements for death certification

Discussion Group

Cathcart United Free Church, Glasgow

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1. Background

The arrangements for death certification and registration have been extensively reviewed and in 2011 new laws were passed by the Scottish Parliament to:

- streamline the current process
- improve the accuracy of death certification, and
- provide improved public health information about causes of death in Scotland.

The Certification of Death (Scotland) Act 2011 introduces a number of changes to the current system. In particular, it introduces checks on the accuracy of Medical Certificate of Cause of Death (MCCDs) by setting up a new national review system. Under the new system, a sample of MCCDs will be selected for review. Sampling and review will be required regardless of whether burial or cremation is chosen. At the moment, a burial can take place before the death is registered. The new system is due to start in April 2015 and from then all deaths must be registered before a body is buried or cremated.

The Certification of Death (Scotland) Act 2011 states that Healthcare Improvement Scotland will implement the Death Certification Review programme and run the service.

The MCCDs Healthcare Improvement Scotland reviews will fall under one of two categories. For Level 1 reviews the medical reviewer will check the MCCD and speak to the certifying doctor. This should take one working day. In addition to these reviews, there will be a smaller number of Level 2 reviews where the medical reviewer will speak to the certifying doctor and also check relevant medical records. This should take three working days.

As a result of these new arrangements, the Scottish Health Council was approached by the project team within Healthcare Improvement Scotland to set up and run a discussion group with attendees at Cathcart United Free Church, Glasgow, on 27 November 2014.

The aims of meeting were to:

- receive feedback on the expedited review and *interested person* review processes and accompanying request forms, and
- discuss general points that should be included in an information leaflet.

2. Overview of the Death Certification Review Programme

An overview of the new review process was provided to the attendees. This was well received with questions taken at the end of the presentation to ensure clarity on the subject.

The following questions and comments were received from attendees.

Question: Do you need to visit the registrar multiple times to register a death?

Response: At present a return visit to the registrar may be required but the use of e-signatures is being explored to remove the need for repeat visits for the bereaved. An individual can currently post the required documents as well which cuts down on required attendance at offices.

Question: Anybody faced with this situation that's not well versed in death certification could find this procedure distressing if told out the blue it will be a two or three day wait caused by the extended review. Doesn't everyone need to know about this?

Response: There will not be mass media campaign on the new procedure but general awareness will be put out there to key personnel. For example if someone is in hospice care then hospice staff will start the discussion. Similarly certifying doctors should also advise of the possibility of a review at an appropriate time. It's not about quantity but the accuracy of information, making it sure it reaches those it needs to.

Question: Felt people would accept knowing death certification can take one to three days in certain circumstances to make sure things are done correctly – should everyone know the reasons behind the review to reduce the shock?

Response: It will be a small number of people that go through this process, but can understand and appreciate the stress on people.

Question: Have faith groups or faith leaders been contacted and involved in awareness raising?

Response: Currently in the process of building a bank of information on different religions and groups to ensure we have information on groups to contact and keep informed. Communication with faith groups is identified in the Scottish Government communications plan and is ongoing.

Comment: It could be worth linking with Presbyteries to communicate with multiple parishes and religious leaders at once.

Response: It has been found easier to link in with some groups over others, but is something that is being worked on to improve.

Question: Is it a purely random selection for 10% for Level 1 reviews, with additional Level 2 reviews?

Response: Yes, the core review process will be totally random for all involved.

Though requests can be made for 'ad hoc' reviews that can look retrospectively at specific causes of death e.g. lung cancer, we can also carry out proactive reviews, e.g. Scottish Government can request reviews for a specific demographic and look at Level 2 reviews for that group. If a review is due to a condition specific request then all involved are told why review happening. The aim is to be as open as possible with people at all stages.

3. Advance Registration

Healthcare Improvement Scotland staff gave the group a short presentation on *advance registration* procedures and took questions on the subject.

The following questions and comments were received from attendees:

Question: Am I right in asking that a funeral can't take place until a review is complete?

Response: In regards to advance registration, there will have to be initial checks carried out e.g. should it be reported to the Procurator Fiscal, what was the cause of death and then we would move forward with the *advance registration* if the MCCD is in order.

Question: How do people coming to registrar office know this *advance registration* is available?

Response: The registrar will tell them and provide a form (also available online). We acknowledge there will be a range of people this affects, including people worried about people being buried in a required timescale. The services required for *advance registration* will operate out of regular hours e.g. Saturdays, evenings, etc. **(There was general approval from attendees at mention of this.)**

Advance Registration Form – discussion

The group was taken through the form layout and accompanying set of questions. The points brought up during the discussion are as follows and reflect views held by the group members and those of the group as a whole.

Is the term “*advance registration*” easy to understand?

- It was felt that the language was a bit formal and could lead to misunderstandings such as the need to complete a form prior to death. “Fast track” was suggested as an alternative as was changing the order of the words to “registration advance”.

- Adequately explaining the process to people may make it easier for them to understand “advance” otherwise it’s not ideal language.
- Noted by attendees that this process still required a second visit to be made by person to a registrar’s office during a very difficult time and that they would like to see this addressed.

Is it easy to understand who can request *advanced registration*?

- Group was concerned that it was unclear whether or not the informant requesting the review was then the designated contact for all future matters. Should it say if one person may take the lead? Group was advised the relationship of who the registering party is, is asked for during initial death registering procedures and from thereafter they are the contact point.

Is it easy to understand why an *advance registration* could be requested?

- The group felt it would read more clearly and cause less distress if the word “practical” came before “administrative”. It would make the form more personable and seem less of an administrative exercise.
- It was also felt the inclusion of one or two short examples would be very helpful to those filling out such a form, especially if it was being done without the support of the registrar e.g. at home.

One attendee commented that: “It could make individuals stop and think maybe this does apply to me.”

Individuals in the group felt if people are distressed, then having something to latch onto and prompt people on how to complete the form could allow them to get it done and move on faster. They also felt this information would definitely be best given beforehand as it was felt as a general rule that more information is always better, especially for those upset and grieving. This would give them time to think, consider and come to terms with a bereavement.

- The wording of the form was felt to need adjustment to make it plainer and bring it in line with language people would use day to day. An example brought up by the group was the use of “live” instead of “reside”.
- It was felt by the group that while the form’s wording was very important, it was also vital that staff advising people about the new processes be well versed in them and properly convey when *advance registration* is relevant. Information needs to be given upfront to people so it is not a shock when needing to register, and it should be written down so they can come back to it.
- There needs to be that human touch to fully explain the matter, this stage is vitally important as is its handling.

Is it easy to understand what will happen after someone asks for an *advanced registration*? (It was made clear by Healthcare Improvement Scotland staff that there would be extra paperwork given along with the form.)

- The group felt that a two-hour plus wait to see what happens next is a lot of waiting about for someone going through bereavement (e.g. person left wondering 'do I go home or wait here?') This is of particular concern if a burial needs to be done within a day.) They felt that initial processes happening over the phone, email or if an answer could be given in around 30 minutes or less would improve things. People need to know what to expect before making contact and if there is local variation.
- There was comment from members that it was "good to have worked on internal review document and pick at it, improve it – privileged!"
- The group raised concerns that, as word of mouth spreads about the *advance registration* process, that more and more people will always have a reason for the review to be speeded up on compassionate grounds, etc?

The group was advised by Healthcare Improvement Scotland staff that this has been considered and will be observed, with ongoing monitoring and evaluation of the process as it goes forward.

- It was thought by the group that with Level 2 reviews being used to check on procedures used and the input of medical professionals that it may be more accepted by family as a good thing to verify accuracy.

Is the *advance registration* request form easy to read and complete?

- It was brought up that some sections of the form (e.g. those around registration numbers/office details) were very complicated and it may be hard to find the information.

Healthcare Improvement Scotland staff advised that portions of the form would be completed by the registrar. It was felt this should be made clearer for those filling the form in alone.

- With regard to the section on "Reason for request", it was felt to be too inaccurate by attendees and needed to make it clear that detail was needed to avoid multiple callbacks chasing information. Perhaps it could be changed to "Please detail request reasons".
- The group discussed the form's introduction and felt it should describe the MCCD in a bit more detail, even giving its full name to avoid confusion for people who may obtain the form in isolation from other materials.

Is there any information about this process that you would like to have explained in more detail?

- The group felt that they had a good handle on the process after discussing it openly and receiving the relevant presentation.

4. Interested Person Reviews

Healthcare Improvement Scotland staff gave the group a short presentation on the *interested person* review process and took questions on the subject.

The following questions and comments were received from attendees:

Question: Is it the case that if a review hasn't taken place or been scheduled that a family member can ask for one to be carried out via this process?

Response: A person can request a review up to three years following the date of death where an MCCD has not already been reviewed by the Medical Review service or the Procurator Fiscal.

Question: If a funeral is planned and about to go ahead can documents requesting a review stop the funeral from proceeding?

Response: A review request being lodged through this process (after registration) won't affect the progress of a funeral. A reviewer can access the MCCD electronically. If the *interested person* review is requested prior to registration, the funeral will not be able to proceed until the review has concluded.

Question: Currently you hear about families refusing to register a death if they disagree with a cause of death, will this affect this?

Response: All deaths should be registered within eight days at most. It is hoped the ability to ask for a formal review will encourage people to register deaths and go through official channels for resolution.

Question: What happens if a family is not happy with the findings of a Level 1 review?

Response: The family would be able to speak to the medical reviewer, explain why they felt the Level 1 review was insufficient and it would be up to the reviewer to decide if it warranted escalation.

Question: Feel cynical saying it but don't see Level 1 review giving much comfort and Level 2 ones being more popular due to the in-depth investigation.

Response: A Level 1 review involves a check of the MCCD to ensure that the information contained is accurate. We don't currently foresee a large percentage of changes that require reissuing of a new certificate, with most changes being small additions to increase clarity or improve practice among staff through education.

Comment: Feel that this aspect needs to be advertised to show people the process is there to drive improvement of service.

Interested Persons Review Form - Discussion

The points brought up during the discussion are as follows and reflect views held by specific the group members and those of the group as a whole;

Is the term "*interested person*" easy to understand?

- All agreed that the term "*interested person*" was easy to understand.

Is it easy to understand who can request an *interested person* review?

- The group felt that the description of the first type of person who could ask for a review did not make it clear that it referred to a relative, carer or friend, in particular the use of the term "qualified" made it sound as if it referred to a professional person.

Is it easy to understand when an *interested person* review can be requested?

- Comment was made that people generally wouldn't know that they could request a review and that it wouldn't be flagged up by the registrar, so how can this message get to relatives etc who do have some concerns about the death certificate.

Healthcare Improvement Scotland staff replied that details of this process will appear in booklets describing the death registration system, but conceded that they were looking for ideas on how to get this message across.

Is it easy to understand what will happen after someone asks for an *interested person* review?

- The group stated that the normal timescales for a response should be indicated on this form. Healthcare Improvement Scotland staff indicated that the timescale was normally within 14 days but that applicants could request an earlier response. The group stated this should also be stated on the form.

Is the *interested person* request form easy to read and complete? Is there anything you think should be changed?

- One attendee commented: “This form doesn’t actually say ‘I want to request a review’ – this should be rectified.” The group was in agreement with this comment.
- One attendee commented: “The form says ‘Interested Person Application Form’ but really should be headed ‘Application for a Review by an Interested Person.’”
- The group felt that in Section A – Applicant Details, there needed to be two methods of contact completed on the basis that if the applicant only completed email address details, one small mistake would mean that the applicant couldn’t be contacted.
- There was discussion concerning Section C, and in particular whether this had to be completed. Healthcare Improvement Scotland staff indicated that completion of Section C was encouraged. Participants asked that this was made clear on the form.
- One attendee commented: “The wording of Section C seems okay – though if it was compulsory I’d be concerned.”

Is there any information about this process that you would like to have explained in more detail?

- The group indicated that the Death Certification Review process had been well explained during the focus group meeting. One participant added that he was happy with the process as long as people would get the information requested under an *interested person* review within 14 days – “that’s important.”

Do you have any further comments about the *interested person* process form?

- One participant commented that she did not like the terminology “disposed of the body” as used in Section A since it seemed synonymous with clearing out an unwanted item, and asked that some other word rather than “disposal” be identified.

Additional comments received on 'post-it' notes:

- Suggested alternative names for the advance review e.g. heightened review, fast review, special circumstances review, increased review request, quickened review, quicker review, hastened review, faster review or quicker registration review.
- Must the registrar call the informant or can it be someone else?
- Make information available for the general public in public libraries, community centres, belief and faith communities.

Participants were asked to forward any other ideas they had regarding any part of the process to the Scottish Health Council who would then pass these to the project team.

Further information about the new arrangements for death certification and registration is available at:

www.healthcareimprovementscotland.org/our_work/governance_and_assurance/death_certification.aspx

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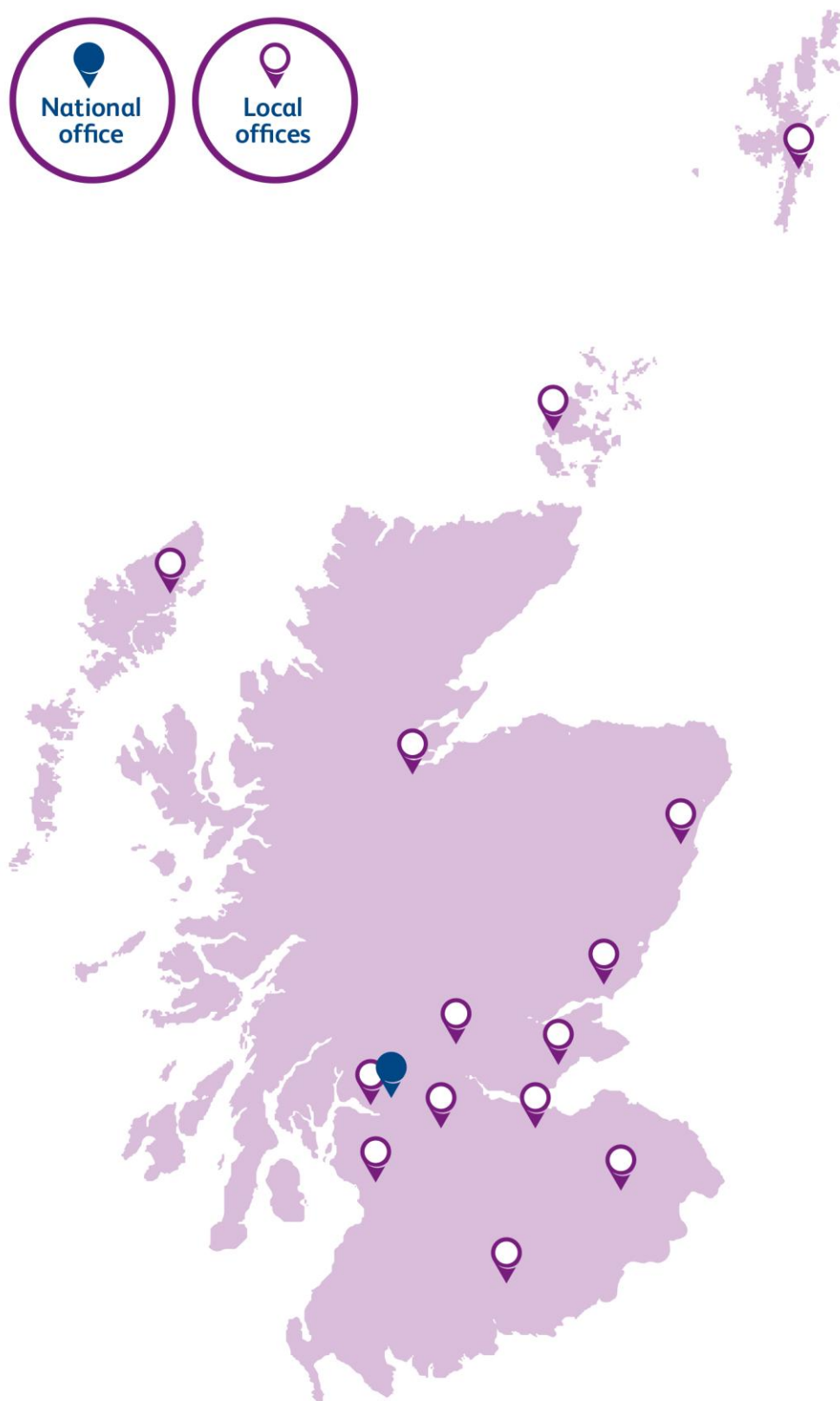
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