

Gathering public views on new arrangements for death certification and registration

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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 2015¹ 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.

2 Support Overview

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 three focus group discussions with members of the public to:

- review request forms, processes and any supplementary information and public information including the information to be contained in a general information leaflet on the Death Certification Review Service.

The desired outcomes of the sessions were that:

- the views of the public will have influenced the Death Certification Review process, and
- for those who have taken part, there will be an increased understanding and awareness of the review process.

3 Support Activities

The Scottish Health Council agreed to:

- organise focus groups within both urban and rural settings
- secure venues
- source participants

¹ Since these focus groups were held, the implementation date for the new arrangements has changed to 13 May 2015

- facilitate and record group discussions
- produce a report of the feedback, and
- evaluate the events.

4 Process

To obtain diverse geographical representation, focus groups were arranged in Orkney, Aberdeen and Dundee.

The project team provided the Scottish Health Council with two sets of 7 questions they wanted to ask under two main headings, namely:

Expedited Review

1. Is the term 'expedited review' easy to understand? Why/why not? Would you prefer another term?
2. Is it easy to understand who can request an expedited review? What is/isn't clear?
3. Is it easy to understand why an expedited review could be requested? What is/isn't clear?
4. Is it easy to understand what will happen after someone asks for an expedited review? If not, can you let us know what isn't clear?
5. Is the expedited review request form easy to read and complete? Is there anything you think should be changed?
6. Is there any information about this process that you would like to have explained in more detail?
7. Do you have any further comments about the expedited review process/form?

Interested Person

1. Is the term 'interested person' easy to understand? Why/why not? Would you prefer another term?
2. Is it easy to understand who can request an interested person review? What is/isn't clear?
3. Is it easy to understand when an interested person review can be requested? What is/isn't clear?
4. Is it easy to understand what will happen after someone asks for an interested person review? If not, can you let us know what isn't clear?
5. Is the interested person review request form easy to read and complete? Is there anything you think should be changed?
6. Is there any information about this process that you would like to have explained in more detail?
7. Do you have any further comments about the interested person review process/form?

The answers to these questions are noted in appendix A.

Further question and answer discussions took place following the set questions above, the results of which are noted in appendix B.

In addition to the questions, comments were given by participants and these are noted in appendix C.

5 Updates and evaluation

In total, 29 people, including two Healthcare Improvement Scotland public partners, attended the three focus groups.

Participants included general members of the public, people who were recently bereaved, registrars, and funeral directors.

Some participants, including funeral directors and registrars, although generally aware of the impending changes, had little detailed knowledge and understanding of the potential impact on established ways of working. Their concerns in essence centred around two distinct themes:

- (i) the impact of the new guidelines on current processes and procedures, and
- (ii) the impact of having to communicate the changes to clients/service users who will be largely unaware of the changes at point of contact, and who by and large will be in varying states of distress when learning about the unfamiliar requirements.

With regard to (i) it was feared that delays to current timeframes would become inevitable if the unique conditions of working in remote and rural island settings on the national periphery were not taken into account.

Concerns relating to (ii) centred around the potential additional commitment (including emotional) required from funeral directors and registrars when faced with having to communicate with, and mitigate the concerns of, service users who are unaware of the new requirements.

Common themes which were apparent during all conversations included:

- the need to change the wording “expedited review” as few people were happy with this terminology
- the need for plain English throughout the process and documentation
- a need for wide publication/promotion of these changes and processes to the general public, and
- out-of-hours doctors should have a leaflet available explaining the new process.

Next steps include:

- Healthcare Improvement Scotland project team to address themes identified by participants
- Healthcare Improvement Scotland to finalise a Frequently Asked Questions document
- Healthcare Improvement Scotland to circulate this report and the Frequently Asked Questions document to participants, and
- this report to be signed off by the Death Certification Review Programme Board and published on the Healthcare Improvement Scotland website.

Appendix A

Questions asked by the project team about the expedited review process and form:

Q1. Is the term 'expedited review' easy to understand? Why/why not? Would you prefer another term?

- One person stated: "No. Took a straw poll round friends before this meeting and it's not easily understood".
- Suggested change of wording included, "speeded up", "not delaying", "fast review", "quicker registration", "faster registration", "fast track", "rapid" and "faster".
- "The language used is key - people around this table have already said they don't know exactly what 'expedited' means".
- "What is the review? What does the word 'review' mean? Is the review going to delay the burial? Can guidance notes be included showing examples of information required to complete form?"
- One person suggested that the word "expedited" is a problem as many people won't have heard of it or it may make them feel vulnerable. They added, "It's vital that terminology is clear and unambiguous as well as generally easily understood".
- "Plain English is better."

Q2. Is it easy to understand who can request an expedited review? What is/isn't clear?

- Two groups thought yes and the flowchart in the presentation helped to explain.
- "Exactly *who* the stated categories of people include, needs to be clearer."
- "It is not clear who can request an expedited review. Is it wise to be limited to three specific categories for expedited review? Would it not empower the registrar if categories were less specific? What training is going to be given to Local Authority registrars?"

Q3. Is it easy to understand why an expedited review could be requested? What is/isn't clear?

- Two groups thought that yes, the categories are clear but it would be useful, under the headings of who can apply, to have a further breakdown of who falls into each category.
- One group referred to their answer given for question two stating they did not think it was clear.

Q4. Is it easy to understand what will happen after someone asks for an expedited review? If not, can you let us know what isn't clear?

- One group thought it would be useful to include the flowchart.
- One group asked whether the medical staff would be available in the timescale allocated, how will people know who to call and at when as every area is different. One person asked whether this could be highlighted in the literature, possibly a fold-out information leaflet, which could be specific to each local area.

- One person suggested: “‘Not stay’ registration² information is too complicated, information could be summarised better. The words ‘not staying’ are complicated”.
- One group thought it was clear.

Q5. Is the expedited review request form easy to read and complete? Is there anything you think should be changed?

- “There are too many words. The background information could be removed and included on a separate information leaflet rather on the form itself.”
- “Simplify the ‘not stay registration’ section and make it less onerous.”
- “Use plainer English.”
- “Is the background information necessary? How long back will the background information go which is included on application form? The majority of people don’t care about what used to be, they just want to know what to do now.”

Q6. Is there any information about this process that you would like to have explained in more detail?

- The general consensus was no.
- One person suggested a comparative list showing the differences between the different types of review as they thought this would be beneficial.

Q7. Do you have any further comments about the expedited review process/form?

- “Many people don’t go immediately to the registrar and they won’t know the importance of doing so in the future. Another reason why this needs to be promoted widely.”
- Two groups thought the supporting statement box was too big and might be intimidating and off putting.
- “Include in the public information leaflet/pack that the registrar can support completion of the form.”
- “Have information that a person can keep after they have handed their form in to the registrar.”
- “Rural areas may encounter practical problems due to locality and access to registrar, will this be considered?”
- “Could the process be done electronically?”

Questions asked by the project team about the interested person review:

Q1. Is the term ‘interested person’ easy to understand? Why/why not? Would you prefer another term?

- The majority of participants thought that the explanation included in the presentation is clear.
- “Include the word ‘review’ – for example ‘interested person review’.”

² “Not stay registration” means that the death can be registered and the funeral can go ahead before the review is complete.

- One group asked whether the word “interested” was specific enough as they thought that anyone could have a casual interest. It was suggested to change the wording to “person with valid interest” or similar, although they were unsure if this was a good enough alternative as the word “valid” can also mean different things to different people.

Q2. Is it easy to understand who can request an interested person review? What is/isn't clear?

- “The first category of applicants who can request this review isn't very clear. Suggest giving a further breakdown of who these people are.”
- “Explain what is meant by ‘carer’ – does this mean professional carer only or does it include unpaid carers? Need to provide more clarity.”
- It was suggested to include an additional tick box for the relationship of the person to the deceased.
- “There needs to be more clarification around this and it will be useful to expand on the Registration of Births, Deaths and Marriages (Scotland) Act 1965.”

Q3. Is it easy to understand when an interested person review can be requested? What is/isn't clear?

- The majority of participants thought it was clear.
- One group thought that it needs to be clear that there is a three-year timescale for the review and asked whether the information should be highlighted in the ‘When someone has died’ literature.

Q4. Is it easy to understand what will happen after someone asks for an interested person review? If not, can you let us know what isn't clear?

- Yes, and no further comments.

Q5. Is the interested person review request form easy to read and complete? Is there anything you think should be changed?

- “Ask for the registration number of any professionals who are requesting an interested person review.”
- “On the form, ask what the reason is for the request.”
- It was suggested that an introductory section would be useful to give guidance about the purpose of the form. It was thought that the form layout is clear but it does not state what it is a form for (to request a review of a death certificate).
- It was suggested that it would be useful to add that the form only applies to deaths after April 2015.

Q6. Is there any information about this process that you would like to have explained in more detail?

- The majority of participants required no further explanations.
- “It would be helpful to have an explanation of what an ‘interested person’ application is. Also the review process is not mentioned on the form.”

Q7. Do you have any further comments about the interested person review process /form?

- Most participants had no further comments.
- “Where do we get information about the interested person review process after three years? Is the information on this review being sent to the Patient Advice and Support Service (PASS)?”
- One group thought that there should be a system in place to support families after the procedures are done.

Appendix B

General comments from focus group members

“Ensure information on the review process is included in an information pack to be given to bereaved families/carers/etc.”

“In small communities, the bereaved may feel stigmatised if people are aware that a funeral is held up for some reason.”

“The process will mean change for both sides and communicating this to the public/stakeholders is important to minimise worry or offence.”

“An information pack is essential – available from health board, funeral director and registrar.”

“Perhaps a local group could get together on this after the Act is in effect?”

“Simple medical terminology is important in a Medical Certificate of Cause of Death, so that the bereaved can clearly understand its meaning.”

“If expedited review is requested/not requested by a relative at the time of initial meeting this may increase ‘family tensions’, depending on individual’s viewpoint.”

“Registrars may be the ‘way in’ for feedback on the process.”

It was thought that it would be useful to set review dates and get stakeholder input.

“Changes will be accepted by the public, but it does mean more bureaucracy at an already difficult time.”

“It’s the registrars who will be on the front line and perhaps mid-process when review is flagged up and this could be difficult for the registrar as well as the relatives.”

It was thought that many people will be unaware of what the current process is regarding certification.

“People may receive an information pack in palliative care situations, but perhaps others do not get this.”

A community nurse mentioned that if a pack is provided, they would like to do a follow-up visit to the bereaved.

“What’s required is an overall communication plan that contains reference to key documents.”

“Suggest alternate names for the ‘expedited review’, for example ‘heightened review’, ‘fast/er review’, ‘special circumstances review’, ‘increased review request’, ‘quicken review’, ‘quicker review’, ‘hastened review’, ‘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.”

“It would be helpful if the bereaved family receive information on the review and the expedited review process from their funeral director/undertaker.”

“The flow chart included in the presentation is very good and easy for non-medical persons to follow – this should be included in the presentation.”

“Reviews happen with cremations just now although in a different way. It is not the quality of care being reviewed here, but the Medical Certificate of Cause of Death itself.”

“When people have just been bereaved and they’re told there is going to be a review, they won’t be able to take it all in. Therefore, it is very important that there is general awareness in the public that these reviews are taking place.” **[The project team also acknowledged the importance of this and said they would feed back people’s concern to the Scottish Government].**

“In addition to a public information leaflet it is hoped to have links to support for bereaved relatives too.”

“At the point of bereavement it’s too late to let people know about the review. It may cost money but promotion of this review process is important. Promotion needs to be done at street level.”

“Information needs to be made available to people before bereavement occurs. Then, if there is a review it won’t be so scary.”

“Give people a range of options for receiving information on the review process.”

“Another avenue that can be used for disseminating information is long term condition groups.”

“This is a health promotion issue – if it’s not done right, it could cause upset/add stress.”

“Speak to health promotion/public health as they’re good at these types of campaigns.”

“Include faith leaders and other pastoral care providers in the promotional work.”

“Adapt the bereavement guide and other related documents to help ensure people know about this review process.”

“Not all registrars are open, even Mon-Fri 9am-5pm, and increasingly an appointment is needed to see them. Therefore, out-of-hours GPs should carry information which can be provided to bereaved family/carers.”

“Seeing own GP, getting an appointment with a registrar – there is a cumulative effect on the time taken to do these things.”

“Regulations need to be absolutely clear about practical steps. These need to be explained in a clear and unambiguous way so that any misunderstanding can be avoided.”

“The availability of expedited reviews as an alternative to the standard review process needs to widely known.”

Following these sessions, Healthcare Improvement Scotland has produced a series of **Questions and Answers** to explain the new arrangements relating to death registration and certification. These can be viewed at www.healthcareimprovementscotland.org/deathcert_qa

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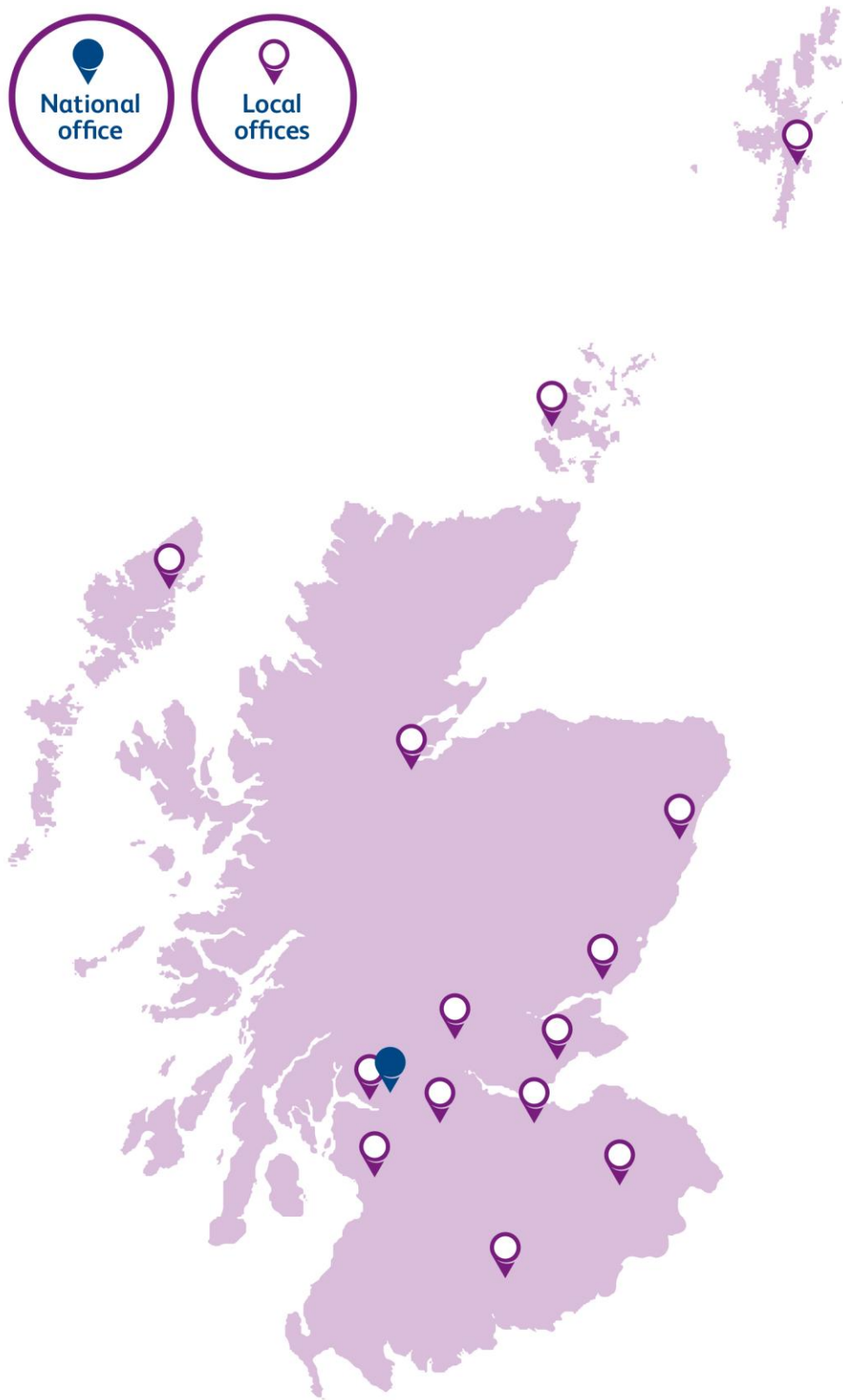
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Scottish Health Council National Office: Delta House | 50 West Nile Street | Glasgow | G1 2NP
Telephone: 0141 241 6308 **Email:** enquiries@scottishhealthcouncil.org

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