Death registration in Ontario

Consolidated research findings from engagements with funeral homes, municipalities and medical communities



Summary: Research Guidelines

Key things to keep in mind when reviewing this work:

1

The anonymity of participants is paramount and must be respected.

2

The findings from this research serve to identify design opportunities to develop a digital solution and processes that reduce blockers and pain points expressed by participants.

They are not intended to precipitate additional "enforcement" or "rules."

3

Workarounds are normal and to be expected; any identified failings are failing of the system, not the people.

4

These findings are primarily based on observations and opinions of research participants. This is particularly important to keep in mind when considering any estimates involving time or percentages.



Summary: Research Sessions

Funeral Homes



9 in-person interviews

2 job-shadowing sessions

8 weeks 11 funeral homes

26 hours of research



Municipalities



10 phone interviews

1 written response

21 municipal staff

10 municipalities

4 weeks 14 hours of research



Medical Community



20 virtual interviews

8 medical practitioners

2 registered nurses

3 coroners

3 public hospitals

2 long-term care homes

2 hospices 14 weeks **30** hours of interviews





Summary: Participant Findings

• There are varying levels of digital maturity among death registrants, ranging from facilities and municipalities that remain completely paper-based to those who are completely digital. Outside of health or corporate networks, different methods and systems are used to complete the same process.







 Workarounds that get the job done quickly are essential, particularly when it comes to transmitting documents. Speed and ease are prioritized over security.







Key demographic information fields such as Name, Age,
 Location, and Cause of Death are common points of error; that lead to blockers (corrections) in the registration process.







• Documents take a long time to arrive to, and from, the ORG. Delays, specifically in issuing Burial Permits and entering death information tasks, instigated by other PoCs (Point of Contacts) in the process, can take up to 8 months. This can include multiple cycles of correcting errors and waiting for updates.







 Users make digital and/or physical copies of documents for recordkeeping and proof of completion purposes.
 Municipalities don't make copies of paper documents but may instead manually enter the information into their respective systems/files.





• Signatures are used to meet requirements, rather than validate information. Practices like pre-signing Medical Certificates of Death (MCODs), Statements of Death (SoDs), or Burial Permits are not uncommon.





Death data accuracy is not a priority until it reaches the ORG. Death-related forms are a small part of medical, funeral, and municipal stakeholders' work.









Funeral home findings



Insights Ø

In the absence of a receipt, one will be created.

- Original paper MCODs and Statements of Death (SoDs) physically move from user to user through the death registration process. Before transferring these documents; funeral home staff copy, scan, and save them for the home's records.
- Copies are also created when funeral home staff fax these documents to municipalities to expedite the Burial Permit process or complete the Cremation Certificate Application.

The "Proof of Death Certificate" is the new death certificate.

 Funeral homes prepare a "Funeral Director's Proof of Death Certificate," which is different from the official provincially-issued Death Certificate. These documents are widely accepted by banks, insurance companies, lawyers and government agencies. This offering from funeral homes has made the process easier and more efficient for families.

Death is already digital.

Funeral homes use commercial-off-the-shelf (COTS) software for client management, billing, and pre-populating and printing information onto government forms such as the SoD, Burial Permit and the Acknowledgment of Death. SoDs are rarely completed by hand.

There is no time for the dead.

- Any errors or issues with acquiring the Burial Permit or Cremation Certificate can stall or halt the death registration process and funeral preparations.
- Due to family arrangements that depend on these documents, funeral home staff are the actors with the greatest sense of urgency to resolve discrepancies/errors. This motivates them to do things such as facilitating MCOD corrections.

Pen and paper do not ensure integrity.

- Existing paper-based processes are filled with workarounds that compromise process integrity in exchange for efficiency.
- Checks that support the integrity of the death registration process, such as signatures, are not always used as intended. One funeral director estimated that "90% [of families] are signing blank forms."

Funeral directors are covert sub-registrars.

- Municipalities have outsourced many of their responsibilities to funeral homes. For example, some funeral homes complete entire Acknowledgement of Death and Burial Permit forms, before going to the municipal office for review and signature.
- Outside of municipal office business hours and during holidays, funeral home staff need to register deaths at municipal subregistrars (e.g local police or fire stations). Sub-registrars have become a preferred place to drop-off forms and pick-up Burial Permits, as they issue them quickly and provide limited or no review.

Insights <a>\mathcal{P}

Digital won't fix death data.

- Current processes are designed to achieve data consistency rather than accuracy (e.g forms are cross-referenced to ensure information matches, but not necessarily that it is correct).
 Designing digital processes with the same logic in mind will not contribute much to improving data quality.
- Funeral directors, medical practitioners and coroners rely on different sources to obtain information about the deceased.
 Family members are a difficult source: they may not know some of the required information, cannot recall it while grieving, or may not answer honestly.
- Some information is not known until after the death has been registered. In response to this, municipal staff may issue Burial Permits but hold on to MCOD and SoD forms for 2 weeks in case new information is discovered.

Financial incentives breed conflict of interest.

- Funeral homes compensate coroners directly for Cremation Certificates, which incentivizes coroners to compete for business. Some funeral homes bypass the online Cremation Certificate Application, opting to expedite the process by directly contacting coroners who they have relationships with.
- Invoicing practices are inconsistent and difficult to audit, causing confusion for funeral directors and revenue loss for coroners.

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Families don't see behind the curtain.

- Funeral homes/directors shield families from the bulk of government processes and paperwork. For example, family members may not review and certify completed SoDs.
- Aftercare services commonly include the cancellation of government identification, notifications to credit bureaus and federal agencies (e.g CRA, CPP) and applications for government death benefits on behalf of the family.



Medical community findings





Behind every good physician is a nurse with a pen.

- Physicians generally do not fill out the entire MCOD, nor liaise directly with other stakeholders in the death process.
- Nurses often fill out the "Information about the Deceased" demographic details in the MCOD, and nurses or administrative staff transfer the document to funeral home staff. Hospitals have entire recordkeeping departments dedicated to scanning, checking, and transferring documents such as the MCOD.
- These additional stakeholders also support quality control (either alerting physicians to errors or making some corrections themselves).

A receipt is worth a thousand words.

- As with funeral homes; facility staff, physicians, and coroners make copies of the MCOD for reference, proof of completion, and/or recordkeeping purposes. Copies can be paper copies, scans, carbon copies (at some hospitals), or faxes (if sent after the fact).
- Medical practitioners (outside of hospitals, which are required to store a copy of the death record) do not always know whether they can make copies of the MCOD but make them anyway.

To physicians, the government is a black box.

- Physicians feel unclear and inconsistent expectations for how MCODs should be completed and handled, and a lack of communication about changes to the MCOD. Rules and policies are disjointed and conflict across different death programs.
- Coroners are the only registrants who receive training from the Office of the Chief Coroner and support on how to complete death-related fields.

Bodies and MCODs aren't a package deal.

- Particularly in palliative care cases, MCODs may be completed off-site and transferred separately from the body. Physicians usually do not handle MCOD transfers themselves, opting to leave them at the scene or having funeral home staff pick them up from the physician's office or the facility later.
- As MCOD completion timelines and transfer methods vary, the SoD may be completed before the MCOD. This means that funeral homes sometimes obtain bodies before death pronouncement and without proof of death.

No two physicians are alike.

Particularly in long-term care, hospices, and rural settings; physicians tend to work at multiple facilities over one week. Each may have different software and death processes. Also, physicians who encounter death often (e.g long-term care physicians) tend to be better versed in processes than those who rarely do it. **Ontario**



Rules without context are made to be broken.

- Some practitioners photocopy or use old versions of MCODs, out of a preference for older formats or because MCODs are perceived as difficult to acquire.
- A variety of workarounds exist to speed up the death registration process. These include completing MCODs for palliative patients before death has occurred, allowing non-physicians to make minor corrections to MCODs, transferring the MCOD through unsecure methods (e.g. unencrypted email, mailboxes), or even (in rare cases) physicians printing information onto MCODs from a patient database rather than writing.
- Family members present on the scene sometimes request and receive copies of the MCOD from physicians and/or police.

Slow and steady won't win this race.

- Physicians and coroners are paid to visit patients, save lives, and investigate deaths. Completing forms like the MCOD or other data entry and searching for information are lower-priority and may cause resentment.
- Hospital physicians need to move bodies quickly to free up space and resources, particularly during COVID-19.
 Palliative care settings are less rushed, but staff typically also aim to move bodies within 24 hours (due to a lack of designated body storage areas).
- The typical MCOD (one not requiring a coroner's investigation or autopsy) takes just 5-10 minutes to complete.

Death speaks many languages.

- Outside of palliative care, determining a deceased's cause of death can feel subjective to physicians. Unless the physician had contact with them prior to their death, it can be difficult to get access to their medical history. At the same time, the MCOD requires a concrete determination of the cause of death.
- Using acceptable terminology is another issue. Over time, physicians learn terms and causes of death that pre-empt returns and questions from the ORG. What they write for Cause of Death may be different from their personal opinion of the most accurate cause.

Your digital don't impress me much.

- Hospital, hospice, and long-term care facilities are trending towards digital or hybrid digital-paper electronic medical records systems, even in rural areas with connectivity issues. At the same time, some facilities remain completely paper-based.
- Individual facilities (or, in some cases, facility networks) each choose their own COTS electronic medical records (EMR) solutions. A variety of different software is in use, with some tailored to specific contexts such as hospices and long-term care homes.
- Physicians are ready for EDR but have very specific expectations of it (e.g. guided cause of death, integration with current systems and pre-filling, delegated access for nurses and admins and offline access with the ability to save). If these cannot be met, EDR will add to their workload rather than decrease it.

 Ontario
- Paper processes are expected to continue.

Municipality findings





There is no 'typical' process.

- Death registration is generally managed by staff in the City/Town Clerk's Office but may take place in another area or by subregistrars. The City/Town Clerk may be actively involved in the process, or delegate tasks to other staff.
- Funeral home staff may arrive in-person with multiple (1-10) Burial Permit requests or provide information in advance by fax/phone so that municipal staff can prepare permits for their arrival. If funeral home staff arrive in person, they may remain on-site to correct errors as the clerk finds them or drop off requests and return later.
- It takes from 2-6 minutes for municipal staff to review a single MCOD and SoD pairing and issue the Burial Permit.
- Municipalities generally invoice funeral homes for batches of Burial Permits on a monthly/quarterly basis, but some infrequent clients pay while requesting the permit.
- Not all municipalities issue Acknowledgment of Death forms. Some municipalities have funeral homes pre-fill their own Burial Permits and drop them off for review and confirmation.

Analog or digital automation: take your pick.

- Municipalities keep records of deaths and other information in custom-built software applications, Microsoft Excel worksheets, or even physical death register books. Some municipalities complete Burial Permits by printing information from their systems onto paper forms.
- Even less tech-savvy municipalities have found ways to automate
 parts of the Burial Permit process: they may use stamps to populate certain fields or have division registrars pre-sign Burial Permits.

In a rush? Wait for the office to close.

- After-hours service for death documents is offered by on-call Clerk's Office staff or sub-registrars from an external department (usually fire or police staff). It is estimated that 20% of Burial Permits were requested after-hours. Some funeral homes may prefer after-hours service for its speed and convenience, but it is:

 1) more difficult for municipalities to coordinate and provide consistent training to the many staff involved, and
 2) after-hours sub-registrars from other departments are often less rigorous than Clerk's Office staff.
- The less rigorous review by after-hours sub-registrars may actually be a draw for some funeral homes to seek out the service.

There's a reason it's called 'snail' mail.

- There is a lag of 1-5 weeks between when municipal staff issue Burial Permits, and when they mail MCODs and SoDs to the ORG. During this time, municipal staff: bundle the documents into a weekly package, enter information from the documents into municipal databases, and may double-check the documents to find/correct additional errors. It is common practice for some municipalities to hold forms for 2 weeks before mailing, in case the Date of Disposition needs to be changed.
- Municipalities may use courier services or Canada Post to send the forms to the ORG.
- When municipalities receive returns from the ORG, they are typically for death registrations completed ~3 months ago.

Insights 🗐

A long, slow goodbye to errors.

- Municipal staff (at 3 municipalities) estimate that 70-90% of the MCOD/SoDs that they receive contain errors. Fields commonly prone to errors include Name (spelling mistakes, order reversed, mismatched between forms, missing middle name), Date of Death (mismatched between forms, date of visitation used instead of date of death), Date of Signing, Disposition Date, Age at Time of Death (miscalculated), Place of Death (missing).
- Every correction of an error must be initialled by the person who made it. For errors found when funeral home staff are on-site:
 - If the error is on the SoD, funeral home staff may be authorized by the funeral director to make corrections on their behalf. In instances of mismatch, funeral home staff often defer to information in the MCOD.
 - If the error is on the MCOD, funeral home staff may correct it prior to arriving at the municipal office. For significant errors, municipal staff may ask them to return and get a correction from the medical practitioner.
- Errors found in the MCOD or SoD after the Burial Permit is issued. are often corrected by municipal staff using sources such as postal code lookup, maps, or online obituaries, Otherwise, they will phone funeral homes or medical facilities.
- Municipal staff estimate that ~5% of the MCODs and SoDs they send to the ORG are returned due to errors. Common reasons for return include names, corrections not being initialled, errors with age at time of death, or errors with date of disposition.

Relationships follow an 'out of sight, out of mind' pattern.

- Through their frequent interactions, municipal and funeral home staff build up strong, first-name rapports over time. Poor relationships or overly arduous quality control practices can prompt a funeral home to shift their Burial Permit business to a neighboring municipality. This motivates municipal staff to be proactive in communicating closures and changes, and in educating staff in funeral homes prone to quality issues.
- Some municipalities have conducted mass mail-outs to local medical facilities to remind practitioners about expectations for MCODs, but these relationships are generally weaker.
- While municipalities have a single point of contact at the ORG for dedicated phone support, many staff expressed frustration at a lack of formal rules and policies related to ORG expectations for data quality. Subjectivity sometimes appears to exist around what is considered an error by ORG vs. a municipality.



Opportunities, recommendations, & design principles



Opportunities & recommendations for EDR

There are a number of opportunities for EDR to improve the death registration experience for participants within our 3 user groups. Below are specific opportunities and recommendations that we are prioritizing in our EDR minimum viable product (MVP) pilot.

System

- Give EDR users access to their past submissions and consider removing policy barriers that prohibit the scanning, copying and saving of forms and their information.
- Design a system that enables two-way communication between all registrants.
- Eliminate the requirement for physical signatures, as they are not currently being used as intended. Authenticated logins can be used instead.
- **Design a user-friendly system:** help registrants make acceptable Cause of Death choices and allow multi-user input with appropriate safeguards.
- Review the current data corroboration model between MCODs and SoDs to ensure that it is meeting program and policy objectives. Consider the viability of consolidating the forms and minimizing data replication.
- Allow registrants to apply for documents through the entire death process online (e.g. Burial Permits), even if it is through PDF forms.

Process

- Consider phasing out the role of municipalities from death registration.
- Design EDR to work with facilities' existing processes, medical technologies, and systems.
- Have a phased roll-out, with contingency plans that include paper forms. At least in the earlier stages, roll out the system only to registrants whose needs can be met and who derive clear benefits from EDR. Set realistic goals, understanding that even institutions with robust and valued electronic medical systems experienced pushback from some staff initially.

Support

- Death registration processes and information need to be available 24/7, 365 days a year.
- Ensure that enhanced communications and outreach accompany the rollout. Stakeholders have mentioned issues with access to information in even their typical processes.
- **Provide support in the system for atypical registration cases and situations** (e.g., bereaved families who are not engaging a funeral home).



Opportunities & recommendations: funeral homes



- Give EDR users access to their past submissions and consider removing policy barriers that prohibit the scanning, copying and saving of forms and their information.
- **Review and redesign processes causing tension** (e.g., death certificates, cremation certificate payment model).
- Allow funeral directors to apply for Burial Permits online by uploading forms and avoid manual data entry.
- Death registration processes need to be available 24/7, 365 days a year. Instant communication between actors would help improve process efficiency.
- **Consider eliminating the role of municipalities** from death registration.
- Recognize Cremation Certificates as a part of the broader death **registration process** and re-evaluate the coroner compensation model.
- Continue research and engagements with users: medical researchers and statisticians, medical practitioners, bereaved families, healthcare facilities, indigenous and northern communities. crematoriums/cemeteries, and associations.



Opportunities & recommendations: medical community

- **Consult with frontline medical staff** as any potential EDR solution is designed and tested.
- Design EDR to work with facilities' existing processes, medical technologies, and systems.
- Design a system that **enables two-way communication** between all registrants and access to training and support.
- Have a phased roll-out, with contingency plans that **include paper forms.** At least in the earlier stages, roll out the system only to registrants whose needs can be met.
- Set realistic goals and expect pushback from certain registrants. Most facilities experienced issues rolling out their electronic medical systems but found that staff came to appreciate them over time.
- **Design a user-friendly system:** help registrants make acceptable Cause of Death choices and allow multi-user input with appropriate safeguards.
- Consolidate insights with funeral homes and municipalities to develop design principles and features.

Medical practitioners also suggested the following specific features:

Save time

- Show only the fields that are relevant to each registrant in order to eliminate duplication.
- Pre-populate information where possible, including using smart fields with automatic calculations (for fields like age), date selection, and locations.
- Limit screens and clicks.
- Integrate with existing systems/logins.
- Target a 5-10-minute completion time end-to-end.

Facilitate communication

- Enable two-way communication with the ORG and between registrants (including feedback on corrections).
- Provide mobile and email notifications that fit users' workflows.

Reflect the nature of work

- Enable registrants to save drafts for later completion.
- Provide a mobile-accessible format.
- Accept electronic signatures (typed or written).
- Ensure that all registrants in the process have controlled, access specific to their role (e.g., nurses, admins, facilities).
- Allow for copies of the record to be saved and printed.

Provide guidance

- Offer in-context help through information buttons, prompts and links.
- Use filtering and drop-downs (e.g. provide a searchable collection of standardized Cause of Death options for the physician to choose from).
- Use clear language and consistent terminology.



Opportunities & recommendations: Municipalities



- Maintain the Division Registrar Manual up-to-date and provide means for municipalities to request copies and have walkthroughs/training.
- Increase ongoing communications and outreach to municipalities to ensure changes and expectations in operational policies are understood and put into place, and that they have a common understanding on delegating duties.
- Provide education, policies, and training on atypical registration cases and situations (e.g., bereaved families who are not engaging a funeral home, family members following up on death registration requests).
- Work with BAO (Bereavement Authority of Ontario) to **ensure** that Death Registration Forms and practical instructions on filling them out are a part of BAO's licensing education curriculum.
- Review the current data corroboration model between MCODs and SoDs to ensure that it is meeting program and policy objectives. Consider the viability of consolidating the forms and minimizing data replication.
- Minimize the rate of hand-filled forms by exploring, in the shortterm, SoDs in a fillable PDF format (for funeral homes that are currently filling them in by hand).

- Ensure that municipalities continue to be able to review incoming data and issue Burial Permits in an EDR system. Some ideas on how to involve them:
 - Enable municipalities to provide forms and data related to death and marriage to ORG through a secure online portal.
 - Enable electronic submission of SoD and/or MCOD, and municipal issuance of Burial Permit and Acknowledgement Form to Funeral Home digitally.
 - Enable municipalities to be able to send messages/alerts to Funeral Homes or Medical Practitioners regarding errors.



Design principles

After reviewing insights and recommendations across all the research sessions, we developed a set of design principles to keep in mind when developing features and processes for electronic death registration.

Flexible and adaptable

- Death registration processes take place within a variety of contexts and systems. EDR cannot be a rigid, linear process but rather adapt to different event sequences.
- EDR will leverage the teamwork that is a natural part of current processes.
- EDR must work on mobile devices and in low-connectivity settings.

Outcome-driven and big-picture

- Consider whether a feature or process will concretely contribute to promote data quality and security. Aim to include stakeholders that work with the data (including Statistics Canada, Service Canada and ORG).
- Workarounds signal opportunities for improvement. Rather than thinking about how to remove them, probe into why they are needed and find ways to formalize them if appropriate.
- While EDR will be iterative and not all features will be present immediately, have an end-state vision for the entire death registration process and consider all work in that context.

Lean and efficient

- EDR will eliminate steps, manual approvals and manual validation where possible.
- Consider how much time each step will take for the registrants.

Communicative

- EDR needs to fill communication gaps between the different stakeholders in the death registration process, as well as between registrants and the ORG.
- Communication sometimes breaks down in these cases, the EDR system itself must be a good communicator.



Appendices

Feature recommendations: medical community



Medical practitioners provided detailed recommendations for specific features of EDR software:

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