Building Capacity for Increased Palliative Care in Africa

A briefing note on the demonstration project on palliative care for elderly African nuns

Ireland and Africa, Palliative care

Ireland is a global leader in palliative care. With leadership comes responsibility.

Africa is one of the least developed regions in the world, with less than 10% of people having access to even basic pain relief at end of life.

Ireland is active in forming palliative care partnerships across Africa. A study last year of palliative care initiatives in Africa, identified 25 projects/operations across 8 African countries with significant Irish input.

Sister Mary Rita, Sr Rose Mary and Sister Jane Frances on the veranda of the convent in Nkokonjeru.

Building islands of coherence through demonstration projects

"When a complex system is far from equilibrium, small islands of coherence in a sea of chaos have the capacity to shift the entire system to a higher order." **– Ilya Prigogine, Nobel Prize winner for Physics**

One of the ways that Africa has been building its own capacity and knowledge in palliative care is through running robust, measurable demonstration projects which are designed and tested within the region to meet the needs of these communities and when proven can be rolled out across Africa. The African Palliative Care Association (APCA) has been actively promoting this approach.

The Irish Hospice Foundation has funded two such demonstration projects over the period 2022 – 25; one on developing a community-led group learning intervention for grief and bereavement in rural communities. The second on improving the end-of-life experiences of patients with advanced disease. Both were piloted with small groups in Uganda, and their measured impact has been considerable. The learning from these demonstration projects has been shared across Africa and written up in academic publications. Proven demonstration projects like these are key in bringing about systematic and long-lasting change.

The spark that led to the demonstration project on palliative care for elderly nuns and the Irish connection

In 2023 at a meeting at APCA, while discussing the progress of the two Irish Hospice Foundation projects, Sr Jane Frances Nakafeero, CEO of Naggalama Hospital, and former Regional Provincial of the Little Sisters of Saint Francis made an appeal for support for palliative care for the elderly sisters in her care.

African sisters dedicate their lives to spiritual and physical care of others through their services in education, health, and other professional areas. They do not render their services for profit. They do not accumulate any personal resources for their care when old and retired. African orders, unlike most of those in countries like Ireland, have few if any assets and very limited financial resources. This has created a situation where these sisters are frequently left without proper palliative care or end-of-life supports and die in unnecessary pain and discomfort.

This is an injustice that needs to be addressed.

There are more than 82,519 nuns in Africa (source Vatican 2023). Assuming 8%–12% of these are elderly there is a cohort of 6,500–10,000 sisters in Africa in need of palliative care at any given time.

Aim

This demonstration project, which commenced in September 2025, aims to develop and assess a model of in-community palliative care for African nuns, which if successful can be rolled out to other religious communities across Africa, and elsewhere.

This project is focused on a group of 50 elderly and retired nuns of the Little Sisters of St Francis (LSOSF) Nkokonjeru, Uganda (the community led by Sister Jane Frances, above). The Little Sisters of St Francis were set up by Irish woman, Mother Kevin Kearney whose work had such an impact on Ugandan healthcare, that hospitals there are often referred to as “Kevina”.

Objectives

The objectives of this project are:

1) To identify the palliative and comprehensive healthcare needs of older retired members of Catholic religious orders.
2) To develop an adaptable, affordable person-centred evidence-based model of palliative and comprehensive healthcare to meet the needs of older retired members of Catholic religious orders.
3) To educate and train health professionals and informal caregivers to deliver the model of care.
4) To pilot the delivery of evidence-based person-centred palliative and healthcare needs to fifty older retired members of Catholic religious orders (this will include provision of essential palliative care medicines as recommended by the WHO in 2017 and provision of equipment essential for dignity at the end of life).
5) Collect data/evidence and make findings readily available.
6) If the model is proven to be effective, consider scaling up the project and rolling this out to other religious orders in Africa.

More detailed objectives in appendix 1

Wider Impact of such a demonstration project

While the demonstration project has been developed with a focus on meeting the needs of elderly sisters it became clear early on that this project had the potential to be another "island of coherence" and have wider impact in the development and reach of palliative care in Africa.

- A key component of this project is the training of formal and informal caregivers using a "train the trainer" model. This world-class and proven training method and material will impact on the communities in which these carers live and work and will be available to be used in other settings right across Africa where it will impact wider communities.
- The knowledge, discussions and energy will impact on faith-run health facilities (which account for an estimated 50% of African health services). In many of these, there is currently limited awareness or knowledge of the benefits of palliative care.
- The model developed will be largely applicable to institutions supporting vulnerable or elderly people (many of which are managed by sisters).

Management of Project, Governance and parties supporting it

The demonstration project has been developed by the African Palliative Care Association (APCA) who are responsible for management of the project, managing the funding and measuring the outputs.

APCA is a pan-African membership organisation, founded in 2004, to ensure that palliative and comprehensive chronic care is understood and integrated into health systems and underpinned by evidence so that no African suffers unnecessarily from life-limiting illness. APCA has implemented over 50 research projects and published 200 papers over the twenty years since its foundation. This work has been delivered with grants totalling over $28m from trusts and foundations, government funding agencies (such as PEPFAR/USAID/CDC, NIH, DFID), research entities and academic institutions in Africa, Europe and North America. APCA has recently been approved to receive Irish Aid funding.

A steering committee has been set up to manage the development, funding and delivery of the objectives of this project and support its rollout. The members of this steering committee are:

- Jean Callanan (Chair), Member of the advisory council of APCA, Advocate for dying well and former Chair of Irish Hospice Foundation.
- Dr Eve Namisango, Executive Director, African Palliative Care Association.
- Sr Jane Frances Nakafeero, CEO of Naggalma Hospital, and former Regional Provincial of the Little Sisters of Saint Francis.
- Dr Julie Ling. Palliative care consultant with WHO, former CEO of the European Association for Palliative Care.
- Jean Duff, Founding Partner of Washington-based The Partnership for Faith & Development.

95-year-old Sr Rose Mary, laughed as her Superior General Sr Rita told us that she used to get into trouble with her as a novice because her embroidery was not up to scratch.

Discussing the project in Nkokonjeru were (from left) Dr Eve Namisango. Executive Director APCA, Sr Jane Frances Nakafeero, Sr Mary Consolata Nakawoojwa, Sister Rita Christine Nakitende, Superior General of the LSOSF and Jean Callanan.

Investment

The total cost of the demonstration project is €131,000. For funding reasons, the project has been divided into two phases. Phase one, which is currently underway (at a cost of €40k for which funding has been obtained) will deliver on objectives 1 and 2 and will be completed by September 2026.

Outstanding Funding for phase two of €91k is being sought.

Timing

Objectives 1 and 2 are in progress and will be completed by September 2026. It is hoped that subject to funding being found, objective 3 (development and delivery of training to formal and informal caregivers) will happen during late 2026/early 2027, with the implementation phase (objective 4) taking place during 2027. The analysis and reporting (objective 5), would be ready for sharing and discussions on roll out (objective 6) by early 2028

Building a wide coalition of support

This is a demonstration project which if successful we hope will provide a model of palliative care that can be rolled out to religious communities. Engagement of church and health related organizations will be key in achieving this roll out.

Engagement and briefing meetings held to date have included:

- International Union of Superiors General and the Anna Trust Foundation (Sr Patricia Murray, in her position as Executive Secretary UISG and more recently as Chair of the Anna Trust Foundation).
- The Pontifical Academy for Life (Monsignor Renzo Pegoraro, and his Scientific advisor, Dr Tina Nunziata Comoretto).
- Archbishop Paul Gallagher, Vatican Secretary for Relations with States (This is obviously not in his area of responsibility, but he was supportive of the project).
- Irish Minister of State for International Development and Diaspora Minister, Neale Richmond and Michael Gaffey, Assistant Secretary Development Cooperation and Africa Division.
- Ambassador of Ireland to the Holy See, Frances Collins.

- Apostolic Nuncio to Ireland, Archbishop Luis Mariano Montemayor.
- Misean Cara (CEO John Moffett).
- Palliative Care Association of Uganda (CEO Mark Donald Mwesiga).

A photographer Grace Gelder has visited and taken photographs of the elderly sisters which will be used to communicate the project. (Thanks to Grace for all the photos featured here).

Further details

The appendix sets out what is involved in each phase of the project. A detailed project proposal is available on request. All questions are welcome.

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Appendix

An outline of objectives and work involved in phase 1 and 2

Phase 1 (Funding secured and in progress)

Objective 1: To identify the - palliative and comprehensive health care needs of older retired members of Catholic religious orders.

We will conduct short interviews with ten (10)older nuns in the Little sisters of St Francis to identify their geriatric, palliative and comprehensive care needs. We will also conduct ten (10) interviews with their formal and informal caregivers as well as the senior managers of Little sisters of St Francis to identify the geriatric, palliative and comprehensive chronic care needs of the older nuns in retirement homes as well what person-centred care would look like from their perspective. The interviews will be transcribed verbatim and imported into Nvivo 14 for thematic analysis. The results will be shared with the stakeholders at a workshop for validation.

Objective 2: To develop an adaptable, affordable person-centred evidence-based model of palliative and comprehensive health care to meet the needs of older retired members of Catholic religious orders

To develop an evidence-based person-centred model of palliative and comprehensive care for of retired members of Catholic religious orders, we will synthesise the local evidence on best practices for palliative and comprehensive care for older persons and the findings from the qualitative formative phase. These will be summarised in a short document and power points for dissemination. We will then convene a workshop with key stakeholders including older nuns, the formal and informal caregivers, experts in ageing, and religious leaders from Little Sisters of St Francis. At this meeting, we will use this evidence and brainstorm on what desirable outcomes of care should be and how these can be best achieved. We will then develop a logic model /theory of change to underpin the evidence-based person-centred model. This is what will shape the services to be delivered to the older nuns. This feedback will be shared with the Uganda Catholic Medical bureau, Ministry of Health and other key stakeholders.

Phase 2 (Funding not as yet secured)

Objective 3: To educate and train health professionals and informal care providers to deliver the model of care.

Based on the findings from objectives 1 and 2, and standards for best practices for palliative care, APCA will develop a curriculum to train health professionals to deliver person-centred evidence-based palliative and comprehensive care for old and retired members of Catholic religious orders. We will also design a short course for the informal care providers. We will train fifteen (15) professional caregivers on palliative and comprehensive care for older persons. These will include nurses, doctors, social workers, chaplains, and allied health workers. The health professionals will then cascade this training by delivering one-week course to informal caregivers. The trained informal caregivers will be supervised by the health professionals to train another 30 informal caregivers (members of the Village Health Team) who care for the older nuns and other members of the religious order from their stations. APCA will continue to mentor the health professionals, who will also continue mentoring the informal caregivers on a quarterly basis. The health professionals will be drawn from the Catholic missionary hospitals where the older nuns commonly seek care.

Objective 4: To pilot the delivery of evidence-based person-centred palliative and health care needs to fifty older retired members of Catholic religious orders.

Upon completion of the training, the health professional and informal caregivers will be allocated older persons to care for using the evidence-based person-centred palliative and comprehensive care. The care will be structured around the thematic areas of the model developed under objective 2. It will involve taking a brief history of the older persons to learn more about their needs, concerns and preferences for care. The use of the palliative care outcome scale, a multi-dimensional assessment and then delivering care based on need.

The trained health professionals are expected to deliver home-based comprehensive palliative care to the older nuns with palliative care needs. They will work in partnership with the proximate Catholic Faith-based hospitals for example St Francis Naggalama hospital in Mukono. These are LSOSF facilities that are already functional and have been caring for these older nuns. They will also be used as a referral centre for older nuns who need hospitalisations or outpatient hospital care. The proposed intervention will be piloted over a period of six months and outcome data will be collected monthly.

The project will ensure that the health facilities stock essential palliative care medicines as recommended by the 2017 WHO Essential Medicines Lists for adults to include the following: Amitriptyline, Bisacodyl (Senna), Dexamethasone, Diazepam, Diphenhydramine, (chlorpheniramine, cyclizine, or dimenhydrinate) Fluconazole, Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram), Furosemide, Hyoscine butyl bromide, Haloperidol, Ibuprofen (naproxen, diclofenac, or meloxicam), Lactulose (sorbitol or polyethylene glycol), Loperamide, Metoclopramide, Metronidazole, Morphine (oral immediate-release and injectable), Naloxone parenteral, Omeprazole, Ondansetron, Paracetamol and Petroleum jelly.

In addition, we will support the partner health facilities to procure essential equipment which includes; patient supportive devices, technologies and supplies, pressure-reducing mattress, nasogastric drainage, or feeding tube, urinary catheters, opioid lock box, flashlight with rechargeable battery, (if no access to electricity), adult diapers (or cotton and plastic), colostomy bags, prostheses as may be appropriate, costs to access radiotherapy for palliative modality for cancer patients where it is needed, mobile phone based platform for medicine and patient tracking as well as for patient health-worker interaction, and access to oxygen. Other needs to address include physiotherapy.

At each monthly visit, we will collect data on multi-dimensional person-centred outcomes using the APCA integrated palliative care outcome scale, then data on quality of life and well-being using the WHO BREF and data on experiences of care using the patient-reported experiences of care measure (the PEQ). At the end of the pilot, if any of the older persons died, we will interview their caregivers about their quality of death and dying using the Quality of Death and Dying index and establish if they had an Advance Care Directive and if their end-of-life care wishes were realised. These are recognised indicators of quality in End of Life Care.

Objective 5: Collect data/evidence and make findings readily available

The findings from the formative work under objectives one and two will be written up into a policy brief, which will be disseminated to key stakeholders. APCA will also hold a webinar to disseminate these findings to a wider audience. APCA and partners will document the processes involved in delivering this novel model of care to

generate the best practices to inform knowledge translation. (The full proposal sets out details of what and how will be measured)

Objective 6 – Scale up: If the model is proven to be effective

APCA will support initiatives to support the scaling up of the best practices to other religious orders in Africa. This will, we hope, involve the Vatican Pontifical Academy of life, the African Bishops and other African religious orders.

Appendix 2

Summary of budget for Objectives 3 - 5

Budget Category	Amount (EUR)	% of Total	Budget Notes
Training and mentorship of Care Providers (Objective 3)	24,610	27%	Curriculum development, training of 15 health workers across 3 sites, and mentorship of informal caregivers.
Pilot Delivery of Care (Objective 4)	12,900	14%	Essential medicines, equipment and consumables, food packages, outreach transport, and stipends for health workers supporting 50 retired sisters.
Data Collection & Dissemination (Objective 5)	12,660	14%	Data collection equipment, ethics fees, exit interviews, longitudinal analysis, and a dissemination workshop.
Sustainability Planning	7,500	8%	Development of a sustainability plan and general awareness materials for the retirement facilities.
Monitoring & Evaluation	8,700	10%	Quarterly data literacy sessions at each site and M&E support from APCA.
Subtotal: Direct Programme Costs	66,370	73%	
Personnel Costs (Coordinators & Grant Admin)	18,000	20%	Project coordinator, site coordinators (3 sites), and grant administration over the 18-month project.
Project Overheads (10%)	6,637	7%	Contribution to project oversight, communications, audit, utilities and office/site costs.
TOTAL PROJECT BUDGET	**91,007**	**100%**	