

Irish Dementia Registry Governance Committee Terms of Reference

Table of Contents

TERMS OF REFERENCE.....	3
ROLE OF THE IRISH DEMENTIA REGISTRY GOVERNANCE COMMITTEE	3
RESPONSIBILITIES OF THE IRISH DEMENTIA REGISTRY GOVERNANCE COMMITTEE	3
MEMBERSHIP	3
MANAGEMENT OF NOCA GOVERNANCE COMMITTEE MEETINGS.....	5
DUTY OF CARE	6
MANAGEMENT OF CONFLICTS OF INTEREST.....	6
CONFIDENTIALITY.....	6
INDEMNITY.....	6
ACCOUNTABILITY & REPORTING RELATIONSHIPS.....	7
APPROVAL AND REVIEW DATE	7

Terms of Reference

Under the Governance Board of NOCA, the Irish Dementia Registry (IDR) Development Project Governance Committee (herein referred to as the Governance Committee) has been convened.

Role of the Irish Dementia Registry Governance Committee

The role of the NOCA IDR Governance Committee is to oversee all matters related to the Irish Dementia Registry. The Governance Committee is not responsible for any executive functions and is not vested with any executive powers.

Responsibilities of the Irish Dementia Registry Governance Committee

The responsibilities of the Governance Committee are to:

- Oversee the development of an IDR dataset, data validation and reporting process
- Oversee a legal framework for IDR
- Approve and provide oversight of recommendations supporting the national implementation of the Irish Dementia Registry (IDR)
- Report and evaluate the impact of IDR on patient outcomes, service improvement, dementia care and policy development and population health
- Engage with the public as well as the local and national healthcare community to garner support for the IDR
- Advise the IDR project team during the IDR development phases

The Governance Committee may delegate specific roles to a sub- committee e.g., preparation of a national/topic specific report, but retain overall responsibility for the role(s) in question.

Membership

Membership of the Governance Committee is multidisciplinary and representative of the core stakeholders. An outline of the IDR core membership is included in Table 1.

Table 1: Membership

Name	Role
Dr Seán O Dowd	Clinical Lead for the National Dementia Service
Paul Maloney	Programme Manager, National Dementia Services
Dr Catherine Dolan	Consultant in Psychiatry of Old Age Co-Lead of Memory Assessment and Support Service
Dr Marwa Elamin	National Clinical Programme for Neurology
Alice McGinley	Community Healthcare Networks (CHN) & Integrated Care Programme for Older People (ICPOP) Lead, Enhanced Community Care Programme & Primary Care Contracts
Prof David Robinson	Consultant Geriatrician Regional Specialist Memory Clinic
Dr Tim Dukelow	Consultant in Geriatric and General Internal Medicine, Cork Community Healthcare Memory Service, Chair of IDR Committee
Matt and Christine Hurley	PPI Representatives with lived experience
Brendan Flynn and Deirdre Dunne	PPI Representative with lived experience
Jeanette Rigeny	PPI Representative with lived experience
Prof Tony Foley	Professor of General Practice, University College Cork
Andy Heffernan	Chief Executive of Alzheimer Society of Ireland
Siobhan Canney	Regional Director of Nursing, HSE West and Northwest Region RHA representative
Noreen Galvin	Assistant Director of Nursing Dementia Quality Improvement Health Service Executive South West
Brian Magennis	Advanced Nurse Practitioner for Older Persons, Mater Misericordiae University Hospital
Fiona Tobin	Clinical Specialist Occupational Therapist, Tallaght University Hospital
Prof Catherine Mummery	Consultant Neurologist, University College London Hospital
Prof Seán Kennelly	Clinical Director of the National Intellectual Disability Memory Service
Dr Nora Donnelly	Senior Research Officer, National Disability Authority
Mairead Creed	Assistant Principal Officer Department of Health
Prof Graham Hughes	Consultant Geriatrician, National Clinical Advisor & Group Lead Older Persons
Dr Mary Browne	Consultant in Public Health Medicine Health Service Improvement
Dr Noreen O' Shea	Consultant in Palliative Care Medicine, Representative of National Clinical Programme for Palliative Medicine
Deirdre Shanagher	Nursing Homes Ireland Representative
Dr Antoinette O'Connor	Clinical Lead Irish Dementia Registry
Andrea Bredin	Irish Dementia Registry Project Manager
Attending member	
Marina Cronin	NOCA Executive Management Team

Tenure:

To ensure organisation knowledge is maintained on the Governance Committee, membership is for the duration of the development project, which is envisaged to be three years.

Chair's Term:

The term of the Chair is for the duration of the development

Resignation:

Resignation before completion of tenure shall be tendered in writing to the Chair, no less than two months prior to the proposed resignation date. In the case of resignation of an individual, who may have been involved, or offering specific advice or guidance in respect of the completion of any particular audit or review of audit data, the Member shall be requested, where possible to ensure all obligations are fully discharged before proposed date of resignation.

Management of NOCA Governance Committee Meetings

Attendance

The Governance Committee meets four times a year (quarterly), with additional meetings where necessary. Prior notice is issued by email. A record of attendance is maintained at every meeting, and this is published in the IDR report at the end of the development phase.

If a member cannot attend, apologies should be sent to the IDR project manager in advance. If a member cannot attend, it may be appropriate to designate an alternate provided prior approval has been secured from the Chair. Inability to attend and contribute to two consecutive meetings will require review of membership and possible re-nomination by the relevant member organisation.

Quorum

The Governance Committee requires the presence of 50% plus one of core members in attendance to establish a quorum for any meeting convened for decision making purposes. The quorum should be maintained throughout the meeting for decision making. In the absence of a quorum and at the direction of the Chair, decisions can be confirmed by email subsequent to meeting.

Decision Making

IDR Governance Committee decisions are made by consensus following discussion by members. In the absence of consensus, members are requested to vote on the decision with the Chair having the casting vote. The IDR Clinical Lead and Project Manager have one vote each on the IDR Governance Committee. Some decisions are reserved for the NOCA Governance Board e.g. endorsement of a report, changes to established policies / procedures. In these cases, the Governance Committee reviews and makes a recommendation to the NOCA Governance Board.

Duty of Care

Duty of Care - Potential patient safety concern and or poor professional performance (not directly related to a NOCA audit).

Should NOCA become aware of a potential patient safety concern and /or poor professional performance (Medical Practitioners Act 2007) they have a duty of care to escalate to the relevant accountable person to ensure appropriate action is taken (PRO 17, Management of patient safety concerns notified to NOCA)

Expenses

Limited funding will be retained by NOCA for patient and public interest (PPI) representatives to cover for vouched travel expenses.

Performance

The Governance Committee shall carry out an assessment of its role, performance and functioning. This will be facilitated by the NOCA Executive Team on an annual basis.

Administrative Support

The Chair and the Project Manager are responsible for the administration of the IDR Development Project Governance committee.

Management of conflicts of interest

In order to ensure the Governance Committee operates in a transparent and unbiased way, all committee members are required to declare any conflict of interest to the Chair in line with the NOCA Governance procedures at all governance committee meetings (PRO 16 Effective management of conflicts of interests in NOCA).

Confidentiality

Members of the Governance committee are nominated by various professional bodies/ representative groups and part of their role is to keep the nominating body informed about developments in the Development Project. The operation of the NOCA meetings is otherwise confidential. **It is a breach of professional confidentiality to divulge any information about specific quality of care issues discussed at the Governance Committee Meeting.**

Indemnity

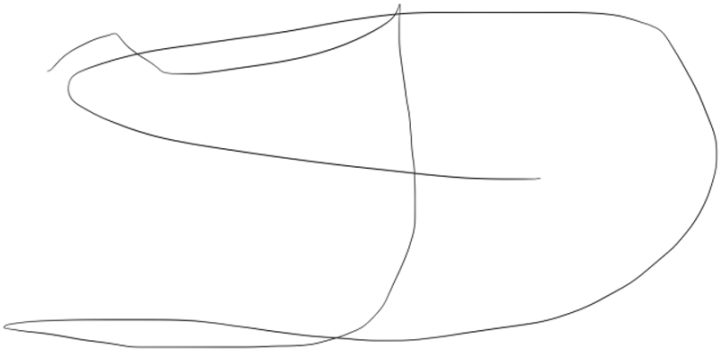
The Clinical Indemnity Scheme (CIS) will indemnify NOCA, its clinical staff and its officers and the convened members of the Governance Committee in respect of all clinical audit activity conducted by NOCA. This indemnity is unlimited, and the State Claims Agency (SCA) will handle any clinical claims arising to completion.

Accountability & Reporting Relationships

The Governance Committee is accountable to the NOCA Governance Board. The NOCA executive team furnish regular status reports on behalf of the Governance Committee to the NOCA Governance Board. The final report will be endorsed by the NOCA Governance Board. Progress reports will be furnished by the executive team to the HSE National Centre for Clinical Audit and Department of Health as required throughout the lifecycle of the project.

Approval and Review Date

The Governance Committee approves its responsibilities and terms of reference at time of set up and reviews performance annually.

Chair Name	Dr Tim Dukelow
Chair Signature	
Date	09.03.26