Irish College of General Practitioners

dementia pathways
For Primary Care in Ireland

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

A Guide to Clinical Audit of Dementia Care in General Practice

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DISCLAIMER AND WAIVER OF LIABILITY

This guide was developed after careful consideration of the evidence available at time of publication. Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content.

This guide is provided for information and educational purposes only. It has been designed to assist General Practitioners (GPs) by providing an evidence-based framework to audit dementia care.

This document is not intended as a sole source of guidance for auditing dementia care and GPs should also refer to professional codes of ethics and relevant national policies and laws.

This guide is not intended to replace ethical and clinical judgment or to establish a protocol for all individuals with this condition. Guidance in this document does not purport to be a legal standard of care. The guidance does not override the individual responsibility of GPs to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family. Adherence to this guide will not ensure successful patient outcomes in every situation

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1.0 Background

The PREPARED project is a programme of work led by the Department of General Practice, UCC to support GPs and allied healthcare professionals in their delivery of dementia care, in order to improve the care of people with dementia in General Practice. PREPARED is funded by The Atlantic Philanthropies and the Health Service Executive as part of the implementation of The National Dementia Strategy (2014). The programme is led by Dr Tony Foley supported by a team of GPs, researchers and a project manager working in the Department of General Practice, UCC.

A key element of the PREPARED programme is supporting General Practitioners (GPs) to audit their care of people with dementia against evidence-based criteria including those published by the ICGP Quality in Practice Committee in *Dementia: Diagnosis and Management in General Practice* (Foley and Swanwick, 2014). This guide has been designed to assist GPs to audit the care of people with dementia.

In addition to this audit guide, a suite of electronic dementia audit tools has been developed in association with the Irish College of General Practitioners (ICGP) and the Irish Primary Care Research Network (ICPRN). These tools are currently available on GP practice management software systems – Complete GP, Socrates, Health One and Helix Practice Manager. The tools support GPs to audit the care of people with dementia by:

- Enabling easy identification of people with a current diagnosis of dementia (the Register)
- Allowing for the identification of people who may not be coded for dementia on practice software systems but where other indicators recorded for the patient suggest that they should be included (the Finder)
- Allowing GPs to upload their data anonymously to a central database and in return receive their practice report.
- Supporting GPs to compare their own practice with other practices.

Completed audits can be submitted annually to the ICGP under the Professional Competence Scheme Framework. This framework recommends that GPs spend a minimum of 12 hours per annum engaged in auditing patient care. It is recommended that all registered medical practitioners should engage in clinical audit, and at a minimum participate in one audit exercise annually.

2.0 What is clinical audit?

Comprehensive information to support GPs undertaking clinical audit is available on the ICGP website. The term 'clinical audit' is used to describe a process of assessing clinical practice against standards to learn if there are opportunities for improvement (NICE, 2002). The Commission on Patient Safety and Quality Assurance (2008, p.152) defined clinical audit as:

'a clinically led, quality improvement process that seeks to improve patient care and outcomes though the systematic review of care against explicit criteria and to act to improve care when standards are not met.'

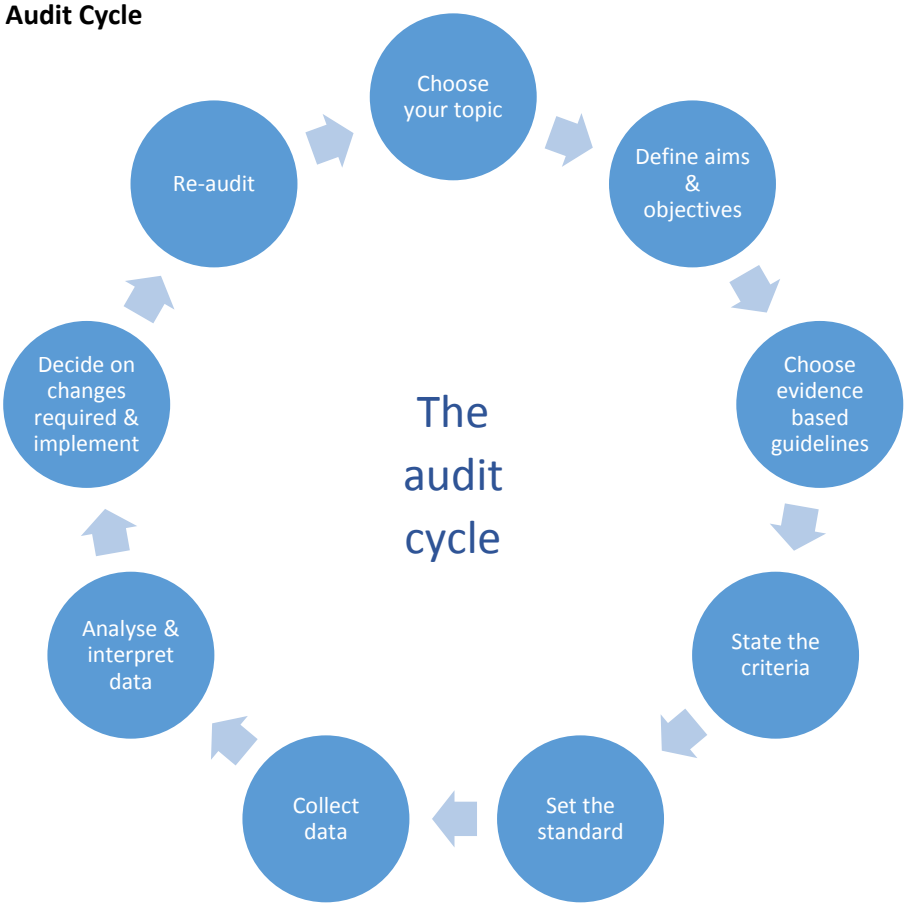
Clinical audit involves:

'... the selection of aspects of the structure, processes and outcomes of care which are then systematically evaluated against explicit criteria. If required, improvements should be implemented at an individual, team or organisation level and then the care re-evaluated to confirm improvements.'

Clinical audit is an essential component of clinical governance (2008, p. 12):

'...constitutes the single most important method which any healthcare organisation can use to understand and ensure the quality of the service that it provides.'

Figure 1: The Audit Cycle



3.0 Choose your topic: Why Dementia?

By choosing to audit an aspect of the care of a person with dementia in your practice, you are contributing to improving their care, which is an international and national healthcare priority. In this section we briefly describe dementia, consider the prevalence and incidence of the condition, examine the impact it has on the lives of patients and families, review the estimated economic impact and examine its impact on GP caseload.

3.1 What is dementia?

Dementia is a syndrome characterised by progressive cognitive impairment causing irreversible decline in global intellectual, social and physical functioning and in many cases, is associated with behavioural and psychological symptoms. There may be memory loss usually related to short-term memory, communication difficulties, changes in personality or mood and problems with spatial awareness. Difficulties performing activities of daily living independently may arise, with instances such as forgetting the names of common objects, times and places, missed appointments and issues around drug adherence. People with dementia may exhibit responsive behaviour and demonstrate impaired insight and judgement. Neuropsychiatric symptoms such as psychosis, anxiety and depression may also present. See Table 1 for more details.

DSM-IV Criteria for Dementia	**DSM-5 Criteria for Major Neurocognitive Disease (previously dementia)**
A1. Memory Impairment	**A.** Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains*: - Learning and memory - Language - Executive function - Complex attention - Perceptual-motor - Social cognition
A2. At least one of the following: - Aphasia - Apraxia - Agnosia - Disturbance in executive functioning	
B. The cognitive deficits in A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning	**B.** The cognitive deficits interfere with independence in everyday activities. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications
C. The cognitive deficits do not occur exclusively during the course of delirium	**C.** The cognitive deficits do not occur exclusively in the context of a delirium

	D. The cognitive deficits are not better explained by another mental disorder (eg, major depressive disorder, schizophrenia)

Table 1: DSM IV and DSM V criteria for dementia

3.2 Prevalence and incidence of dementia

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in people over 65 years of age (Hoffman, 1991; Launer, 1992). Dementia prevalence is rising. Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades (Trepel, 2011). In 2009, there were an estimated 41,700 people living with some form of dementia in Ireland. It is expected that this figure will rise to 147,000 by 2041 (Cahill et al., 2012).

3.3 Burden on patient and family

Most importantly, the adverse impact of dementia on the lives and functioning of those living with the condition and on carers is profound (Rabins et al., 1982; Papastavrou et al., 2007). There is a significant personal and social cost to dementia care, as the majority of PwD live at home cared for by family members. In an international consensus consultation, disability from dementia was accorded a higher disability weight (0.67) than that for almost any other condition, with the exception of severe developmental disorders (WHO, 2004). A meta-analysis of predictors of transition into a nursing home in the USA found that cognitive impairment was the health condition that most strongly predicted transition, with a 2.5 fold increased risk (RR 2.54, 95% CI: 1.43-4.51) (Gaugler et al., 2007). Therefore, irrespective of the approach taken to measure its impact, it is clear that dementia very significantly affects the lives of PwD and their family members.

3.4 The economic argument

Due to the progressive nature of dementia, costs of dementia care in Ireland are considerable. The ARCH study (Regan, 2014) estimated the total baseline annual cost at approximately €2.32 billion, with almost half of this cost attributable to the cost of care provided by family and friends. Other studies suggest an average annual cost per person with dementia of approximately €40,500 per annum (Regan, 2014). Costs associated with dementia care are more than for stroke, heart disease and cancer (Regan, 2014).

3.5 The GP Caseload

General Practitioners are often the first healthcare professionals to be consulted when dementia is suspected. Currently, the average GP diagnoses one or two new patients with dementia each year and will have 12 to 15 patients with dementia in an average list size (Iliffe et al., 2009). Primary care

dementia workload will inevitably increase as our population ages. Early recognition is not easy because of the insidious and variable onset of symptoms. 'Timely' diagnosis of dementia and early intervention is advocated by clinical guidelines and national strategies, however, a diagnosis gap has been identified and it is estimated that half of all cases of dementia are not formally diagnosed. Confirmation of the diagnosis can take up to 4 years and diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed. GPs experience difficulty in diagnosing and disclosing a diagnosis of dementia to their patients citing difficulties differentiating normal ageing from symptoms of dementia, lack of confidence and concerns about the impact of the diagnosis on the patient (Foley et al. 2017).

3.6 The Irish National Dementia Strategy

The National Dementia Strategy sets out a number of principles to underpin the provision of care and supports for people with dementia including:

- Taking account of dementia in the development and implementation of existing and future health policies;
- Encouraging the participation of people with dementia in society and in their own communities as fully as possible for as long as possible;
- Prioritisation of end-of-life care in an appropriate setting for those with dementia;
- Appropriate training and supervision for all those caring for or providing services to people with dementia;
- Directing resources to provide the best possible outcome for those with dementia, and for their families and carers.

A key stream of the strategy focuses on improving the quality of care for people with dementia in the community. Therefore by auditing dementia care in General Practice you are contributing to a whole system effort to improve dementia care.

4.0 Defining Aims and Objectives

4.1 Choosing an area of dementia care to audit

So now you have decided to conduct a dementia related audit, how do you decide what aspect of care to focus on? Priority areas for healthcare audit are usually activities that are considered to be high risk, high volume, high cost and/or high complaint areas. It is recommended that key stakeholders are identified and involved from the beginning of an audit (Ashmore et al. 2011) so you might decide to brainstorm potential dementia care related topics with your colleagues and to agree the aim and objectives from there. Other stakeholders include people receiving the services or perhaps funders. Involving patients and caregivers might also be feasible at this stage. See Box 1 for an example of the outcome of brainstorming for Dr Murphy and the practice care team.

During a weekly practice care team meeting Dr Murphy suggested conducting an audit of dementia care to the PCT. She suggested brainstorming as a way to agree the audit topic area. Using a flipchart Dr Murphy asked the team to consider aspects of dementia care that the team felt were high risk, high volume, high cost or high complaint areas.

The practice secretary identified a considerable **waiting list for the memory clinic** (high volume) and received a lot of **requests for information about community supports** for people with dementia.

The Public Health Nurse noted that she had received a number of complaints from family members that **patients with dementia were often sent to A&E when presenting out of hours to GP services**.

The practice nurse noted that **people with dementia were presenting with flu** and this may be increasing costs associated with the management of the condition.

Dr Murphy's partner was concerned about **prescribing of antipsychotics for behavioural and psychological symptoms of dementia.**

The palliative care clinical nurse specialist asked **how many people with dementia had made advance care plans** as she was seeing a number of cases where families were unsure what the person with dementia wanted at end of life.

As the brainstorming continued Dr Murphy wondered exactly **how many patients with dementia, and suspected dementia** were on their books.

Box 1: Brainstorming dementia audit topics with the Primary Care Team

Following this brainstorming exercise, it was agreed by the team that the first step must be to find out the number of people with a confirmed diagnosis or suspected diagnosis of dementia. Starting with establishing baseline data is **not** an audit. Audits go beyond simply 'counting' or 'examining' as an audit focuses on achieving improvement in practice. However, before an audit of care commences, it is important to determine baseline data regarding the number of people with

dementia by identifying the dementia population in the practice. Audits of the other areas of dementia care as outlined in Box 1 can then be prioritised once the baseline is established. These topics could be aligned to the Donabedian (1966) classification system of structure, process and outcome to focus on areas of practice from which to choose a topic. In the event that your team is finding it hard to prioritise an audit topic, scoring systems are available to help you see further examples of scoring systems for prioritising audit topics may be found at: http://www.hqip.org.uk/assets/Downloads/Clinical-Audit-Program-Guide-and- Guidance-Tools.pdf

4.2 Writing the aim and objectives

To define the aim of your dementia audit, consider what it is that you hope to achieve i.e. the overall purpose of the project. It should be related to the rationale behind choosing your audit topic. The aim can be written as a statement about what you want to happen as a result of the audit. Statements should be phrased positively, to ensure that the audit brings about improvements in practice. Buttery (1998) suggests some verbs that can be used to structure the audit aim and objectives e.g. Improve, Ensure, Change, Increase, Enhance

Dr Murphy and her team agreed to establish a baseline and profile of patients with dementia and then to conduct an audit of flu vaccinations in this population as outlined below.

Box 2: Example of audit aim and objectives

Audit Topic: Dementia

Aim: To improve the care received by patients with dementia at Castlerock Primary Care Centre.

Objectives: (1) To identify patients with a current diagnosis of dementia; (2) To identify patients who may not be coded for dementia but where other indicators recorded for the patient suggest that they should be included; (3) To obtain a profile of people with dementia and suspected dementia in the practice and (4) To ensure that all people with dementia and those suspected with dementia in the practice receive the flu vaccine.

5.0 Choosing Evidence Based Guidelines and Standards

Once the team has agreed the audit topic, broad aim and objectives, it is necessary to select the evidence-based standards or guidelines to inform the development of explicit audit criteria. In the area of dementia care in general practice, Irish documents that identify what good quality dementia care should look like can assist you to develop audit criteria:

ICGP Quality in Practice Committee Dementia: Diagnosis and management in general practice.

IHF Guidance Dementia Palliative Care Guidance Documents (includes documents specific to advance planning, bereavement, communication, ethical decision making, medication management, pain and hydration and nutrition)

National Dementia Strategy

Other international standards and guidance also exist:

UK: NICE Dementia Guidance (includes quality standards, guidelines and evidence reviews across all aspects of dementia care.

Guideline 86: Management of patients with dementia

Europe: EFNS Guidelines for the Diagnosis and Management of Alzheimer's Disease

BMJ Evidence Summary – Dementia Focused

Cochrane Library Systematic Reviews (search for dementia and associated relevant area)

Following baseline data collection, Dr Murphy's team reviewed the Irish evidence base to establish criteria for vaccination uptake for people with dementia.

Evidence Reviewed: ICGP Quality in Practice Committee Dementia: Diagnosis and management in general practice.

Outcome of Review: This guidance document states *"Immunisation guidelines recommend flu vaccine administration for residents of nursing homes and long stay institutions, as well as in persons aged 65 years and over".* The guidelines referenced are National Immunisation Advisory Committee (NIAC) Immunisation Guidelines (2013).

Dr Murphy consulted the NIAC page on the HSE website and noted that a more recent version of the guidance is available, published in 2015. The recommendations outlined above had not changed, however the team agreed to cite the most recent guidelines in the audit report.

6.0 Stating the Criteria

Once you have found the relevant standard or guidance for your chosen topic you can write your audit criteria. When writing the criteria think **'SMART' (Box 3)**

Specific	•Use clear, unambiguous language- no jargon! •The criteria should mean the same thing to everyone who reads it.
Measurable	•Is the information required to answer your standard available? •If data is collected retrospectively, how will you know if it's a failure of practice or a failure of documentation?
Agreed	•By the team involved in the care process
Realistic	•To the area of care given your practice
Theorectically Sound	•Evidence based and acceptable

It is recommended that when conducting an audit, if the topic is relevant to a relatively small number of patients, then you should examine a greater number of criteria for these patients.

In consultation with the practice team, the audit criteria were agreed by Dr Murphy with her team. They considered the need to be 'SMART'

Audit Criteria: Patients (regardless of age) with a confirmed or suspected diagnosis of dementia living in nursing homes or long stay institutions will receive an annual flu vaccine.

Patients with a confirmed or suspected diagnosis of dementia living at home aged 65 years and over will receive an annual flu vaccine.

7.0 Setting the Standard or Target

When the audit criteria have been developed, it is important to agree the standard or target that you will meet. Usually, this is 100%, since if the criteria reflect best practice, then everyone should be entitled to receive that level of care. However, it may be appropriate to set the target at a figure lower than 100% if you are comparing outcomes against a national benchmark or if you are referring to a practice that will never occur (in which case the target is 0%).

In addition to setting the target, it is necessary to consider the exceptions. Exceptions are justifiable reasons for not providing the level of care specified in the criteria agreed. It is important that these exceptions are agreed by the whole team in advance and are not used to disguise situations where a person made a choice in light of lack of information. Examples of exceptions include:

- Patient going on holiday / living abroad for a significant time
- Patient not consenting to a treatment
- There is a contra-indication to administration of the vaccine

Dr. Murphy's team decide on a target of 75% in line with the recommendation in the ICGP Flu Audit Toolkit

75% patients (regardless of age) with a confirmed or suspected diagnosis of dementia living in nursing homes or long stay institutions will receive an annual flu vaccine.

75% patients with a confirmed or suspected diagnosis of dementia living at home aged 65 years and over will receive an annual flu vaccine.

8.0 Collect the data

When the topic has been selected, the aim and objectives agreed, standards or guidance identified, audit criteria defined and targets set, it is time to commence data collection. In our example, Dr Murphy has four sets of data to collate:

(1) Number of patients with a current diagnosis of dementia;

(2) Number of patients who may not be coded for dementia but where other indicators recorded for the patient suggest that they should be included;

(3) The profile of people with dementia and suspected dementia in the practice and

(4) Percentage of people with dementia and those suspected with dementia in the practice who received the flu vaccine.

This data can be collated manually from patient records, using a bespoke data collection tool that you can design to collate the data, or it can be collated electronically via your record management system. If you are a member of the IPCRN and have sent data using the dementia uploader, the data for many areas of audit of dementia care will be contained in the practice report you receive. The ICPRN dementia uploader report includes:

- demographics of people coded with dementia
- the number of people prescribed antipsychotic medications in the last 12 months
- the number of people prescribed Cholinesterase Inhibitors in the last 12 months
- smoking status
- flu vaccination in the last 12 months
- alcohol consumption
- consultation frequency and consultation visit code
- prescribed medications in the last 12 months

However, it is important to note, that the uploader will only show this information if it has been recorded on the practice system by the GP. The data report also highlights change in statistics since the last report, as well as comparing the data from your practice, to other practices using the system.

In the event that a diagnosis of dementia has not been made, it may be possible to detect people with suspected dementia through prescription of certain medication e.g. Cholinesterase Inhibitors.

You audit data should include current / recent patients.

Dr Murphy used the dementia patient register and the dementia patient finder tools on her software system. Dr Murphy is also a member of IPCRN and used the dementia uploader report to assist with the audit.

The report indicated that 35 people have a diagnosis of dementia currently coded with a dementia on the practice software system. 63% of these were female and 12 were aged between 90-94. 10 people had been prescribed Seroquel and 5 were prescribed Haloperidol in the last 12 months. She also identified 14 additional patients who were not diagnosed with dementia but were being prescribed Donepezil (n=10) and Memantine (n=4).

She discussed these cases with the team and it was agreed that it in all 14 cases, these people had a diagnosis of dementia (but that this had not been coded). 22/49 patients (44.9%) had the flu vaccination in the last 12 months.

Dr Murphy discussed this with her team and it was agreed that this figure was very low compared to the criteria set for the audit (75%). However, the team suggested that this low figure could reflect lack of electronic record keeping and did not include the additional patients identified. Furthermore, there is a possibility that since some of the patients were living in a residential care setting for older people, that they may have had their flu injection there, administered by another GP.

The next steps are to:

- Analyse and interpret your data via comparison with your target
- Decide on the changes that need to be made and implement these changes
- Re-audit your practice to determine if an improvement has been made

Please consult the ICGP Audit Guide available at www.icgp.ie/audit for more information on data analysis and report writing. If you have used the IPCRN data uploader, it is possible to re-run the data check after the quality improvements have been conducted and this will allow you to compare data pre and post quality improvement.

Dr Murphy searched the empirical literature to examine evidence-based ways to increase uptake of the vaccine in primary care. She came across a study in BMJ http://bmjopen.bmj.com/content/2/3/e000851 and Dr Leonard's paper on the ICGP website

The quality improvements agreed by the team specific to increasing flu vaccinations agreed included:

1. A surgery notice on the door of the waiting room to remind patients to discuss the flu vaccine with their GP or practice nurse

2. A letter to all people with dementia to remind them about their flu vaccination

3. A notice on the cupboard where the vaccines are stored to ensure GPs document administration of the vaccine on the practice software

4. Liaise with staff in the nursing homes to ensure flu vaccination records are communicated to the GP.

The audit cycle will be completed following the 2016/2017 flu season to assess whether this simple and cost effective method has any effect on increasing vaccination uptake rates.

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