INFORMATION ANALYSIS DIRECTORATE

Raw Disease Prevalence in Northern Ireland

User Guidance Notes

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1. Introduction

1.1 With the introduction of the General Medical Services contract in April 2004, a quality framework of indicators was developed for general practice, the Quality and Outcomes Framework (QOF). The QOF measures achievement against a range of evidence-based indicators. An integral part of the QOF is the collection of prevalence data to allow practices to case find those patients that require specific management.

1.2 Prevalence is a measure of the burden of a disease in a population at a particular point in time (and is different to incidence, which is a measure of the number of newly diagnosed cases within a particular time period).

1.3 As a means of stabilising GMS, QOF was suspended for payment purposes for the 2023/24 year, with no financial detriment to general practices. Although QOF was suspended, disease registers are still maintained by general practices, allowing prevalence data to continue to be collected. The DoH prevalence release for 2023/24 will therefore proceed as normal. However, there will not be a QOF achievement publication for 2023/24. Information relating to how prevalence is used within QOF achievement is still relevant for previous releases.

1.4 In a standard QOF year (i.e. when QOF is not suspended), prevalence data is used to calculate points and payments within each of the clinical domain areas and a number of the public health domain areas. Specifically:

- Points can only be awarded to a practice for a given domain area if the practice can produce a register of patients with that disease or condition; and

- the number of pounds per point in each domain area is adjusted up or down according to each practice's prevalence for each disease or condition, relative to the estimated regional Northern Ireland prevalence for that disease or condition.

1.5 The amount by which the pounds are adjusted up or down is known as the Adjusted Disease Prevalence Factor (ADPF). The aim of the prevalence adjustments in each of the clinical indicator groups is to deliver a more equitable distribution of payments in the light of different workloads that practices face in achieving the same number of points. Practices with a high prevalence of a specific condition or group of conditions will receive more pounds per point for the relevant indicator group than practices with a low prevalence of the same condition or group of conditions.

1.6 The data source for QOF is the General Practice Intelligence Platform (GPIP)/QOF (GPIP/QOF), a Northern Ireland IT system that supports the QOF process. The application of standardised coding across general practices, ensures consistency in prevalence data collection.

1.7 Registers relate to each of the indicator groups within the clinical domain and public health domain of the QOF. The information systems which underpin the QOF hold the numbers of

patients on each of these registers, for each participating practice. For example, there is a register count for all people diagnosed with Coronary Heart Disease (CHD) at each practice.

2. Interpretation of the Prevalence Figures

2.1 The QOF prevalence figures presented here are raw prevalence rates. This means that they take no account of differences between populations in terms of their age or gender profiles, or other factors that influence the prevalence of health conditions.

2.2 A QOF prevalence rate is simply the total number of patients on the register, expressed as a proportion of the total number of patients registered with a practice at one point in time (the denominator). All prevalence registers are recorded as at National Prevalence Day each year. National Prevalence Day was initially 14th February each year; from 2009 onwards, National Prevalence Day was changed from 14th February to 31st March to bring it into line with National QOF Achievement Day. See section 3 for information on age-specific registers and their associated denominators.

2.3 The registered list population is taken as at January of the relevant year, for example, for the QOF year 2004/05, the list size was taken at January 2005. The registered list population will differ from the mid-year estimate of population of Northern Ireland due to a combination of factors. There can be a delay in the GP lists being updated when patients join or leave the practice, for example in the case of births, deaths or when patients arrive into or leave Northern Ireland. Individuals who live in the Republic of Ireland but work in Northern Ireland are entitled to medical care in NI so will be included in the GP lists; however, there are also people who live in the Republic of Ireland but use "addresses of convenience" in Northern Ireland to register with a GP and access free health care.

2.4 It is important to emphasise that QOF registers are constructed to support indicators on quality of care, and they do not necessarily equate to prevalence as may be defined by epidemiologists. For example, prevalence figures based on QOF registers may differ from prevalence figures from other sources due to coding or definitional issues.

2.5 Care should be taken when looking at trends in prevalence over time. Year-on-year changes in the size of QOF registers are influenced by various factors including: changes in prevalence of the condition within the population; demographic changes, such as an ageing population; improvements in case finding by practices; and changes to the definition of the registers.

2.6 The criteria for inclusion on the QOF registers can be very specific and may not be comparable to other sources of prevalence data. For example, the asthma register excludes patients who have not been prescribed asthma-related drugs in the previous twelve months. Care should be taken to understand definitional differences, for example when comparing QOF prevalence with expected prevalence rates using public health models.

2.7 New registers should be treated cautiously in the first few years of reporting as they are still being established and validated. Apparent increases in prevalence may be due to improvement in recording and case finding by GPs, rather than a true increase in the prevalence in the population.

2.8 QOF prevalence rates can also be affected by other factors such as:

- health care seeking behaviour - people differ in the readiness with which they seek health care when they are not well;
- access to services - people are more likely to consult for a condition if services are readily accessible;
- diagnostic practice - it is impossible to completely standardise the methods clinicians use to make diagnoses; and
- data recording - there may be variations in the completeness and accuracy of practice records.

2.9 Note that some of the clinical domains are not measuring prevalence of a disease or condition. For example, the smoking indicator relates to the percentage of patients aged 15 or over whose notes record smoking status in the preceding 3 years. This indicator only examines whether smoking status is recorded in the patient record and cannot be used to determine prevalence of smoking. Note that the smoking register was removed from 2014/15.

2.10 In several cases, the definition of a register has changed over the years. For example, the Heart Failure 3 register originally included all patients with heart failure due to left ventricular dysfunction (LVD). From 2013/14 the definition was amended to include only patients diagnosed with left ventricular systolic dysfunction (LVSD), so the register is no longer comparable to previous years.

2.11 Some clinical areas have 'resolution codes' to reflect the nature of diseases; others, such as the cancer register, do not. For example, where a patient has been diagnosed with hypertension and been subsequently successfully treated, if there is a 'hypertension resolved code' present in their record after the latest hypertension recording, they will be removed from the register.

2.12 The QOF diabetes register does not distinguish between types of diabetes and patients are captured in a single register. In 2012/13, the register definition expanded to include all diagnoses of diabetes as defined by the WHO (type I, type II, genetic, other and uncertain); previously the register only covered type I and type II. Gestational diabetes is excluded from the register.

3. Age Specific Registers & Prevalence Rates

3.1 The definitions of some QOF registers are restricted to include only persons over a specific age. For QOF payment purposes, the QOF prevalence rates use as their denominator the total number of patients, of all ages, registered at January of the relevant year. This means that, for these conditions, the QOF-reported prevalence will appear lower than would be the case if the

age restriction was also applied to the population denominator. For those indicators that have a specific age range, the raw prevalence is presented in both forms, calculated using the appropriate subset of the registered lists as the denominator for the age-specific register, in addition to the standard QOF prevalence calculated using the total number of patients of all ages.

3.2 Two clinical areas within the current QOF for 2023-24 (chronic kidney disease and diabetes) are based on clinical registers that relate to specific age groups:

- The chronic kidney disease (CKD) register includes patients aged 18 years and over.
- The diabetes register includes patients aged 17 years and over.

3.3 Note, 6 registers which have now been removed from the QOF were also age-specific (depression, epilepsy, osteoporosis, rheumatoid arthritis, obesity and learning disability). Note, CKD was removed from the QOF in 2014/15 and was re-introduced in 2022/23.

4. Limitations of the QOF Prevalence Data

4.1 The QOF data is only collected centrally at practice level. Patient-specific data is not required to support the QOF payment system. There is no centrally-held data on patient details that can be directly linked to the prevalence registers, so the registers cannot be analysed by patient characteristics such as age or gender.

4.2 The collection of the QOF data at an aggregate level for each practice also precludes robust analysis of co-morbidity. Many patients are likely to suffer from co-morbidity, i.e. they are diagnosed with more than one of the conditions included in the QOF, but this cannot be analysed due to the lack of patient level data. For example, information is collected for each practice on patients with coronary heart disease and on patients with COPD, but it is not possible to identify or analyse patients with both of these diseases.

5. Registers Presented

5.1 There are 4 domains in QOF: (i) clinical (ii) public health (iii) records & system and (iv) patient experience. The clinical domain currently has 15 areas; 14 of which have a disease register (the influenza vaccination area has an "at risk" population). The areas are as follows:

- Asthma
- Atrial fibrillation
- Cancer
- Chronic Kidney Disease
- Chronic Obstructive Pulmonary Disease
- Coronary heart disease
- Dementia
- Diabetes mellitus

- Heart failure
- Hypertension
- Mental health
- Non-diabetic hyperglycaemia
- Palliative care
- Stroke and transient ischaemic attack

Note heart failure has a sub-register; it has 2 registers to calculate the ADPFs for different indicators within the area. There are therefore 15 registers within the clinical domain.

5.2 The public health domain has 1 additional service; cervical screening, which does not have a register instead it has a target population group.

5.3 The online spreadsheet presents register sizes and raw prevalence rates for the latest year at general practice, Local Commissioning Group (LCG) and GP Federation level for 15 registers (all within the clinical domain). At NI level, registers and raw disease prevalence rates (including age-specific rates) are also presented for registers that have subsequently been removed from QOF (of which there are 11). Note that chronic kidney disease was removed from QOF in 2014/15 but was re-introduced in 2022/23. General practice level and LCG data is presented from 2010. Data by GP Federation is presented from 2017 onwards.

5.4 In the "Raw Disease Prevalence in Northern Ireland 2023/24" annual report, register sizes and raw disease prevalence are presented for 14 clinical conditions:
Asthma, Atrial Fibrillation, Cancer, Chronic Kidney Disease, Chronic Obstructive Pulmonary Disease, Coronary Heart Disease, Dementia, Diabetes, Heart Failure, Heart Failure due to LVSD, Hypertension, Mental Health, Non-Diabetic Hyperglycaemia and Stroke and Transient Ischaemic Attack.

FLU and PC are not presented in the annual report. Influenza vaccination is not a measure of prevalence; this refers to those at risk or aged over 65 who have received the seasonal flu vaccination. Palliative care is difficult to interpret as by its very nature patients join and leave over a short period of time.

For the latest year of data, prevalence rates are presented by LCG and GP Federation. Disease prevalence distribution across general practices is also presented for the latest year. Time series data is presented for Northern Ireland for those years in which the register definition has remained consistent.

5.5 The interactive dashboard presents register sizes and raw disease prevalence for the same 14 clinical conditions. Seven years of data are available by LCG and GP Federation. Age-specific rates are presented in hover labels where appropriate.

6. Definitional Changes to Registers

6.1 QOF registers for six clinical areas have maintained consistent definitions since April 2004: asthma, stroke and TIA, cancer, CHD, COPD, and hypertension.

6.2 The definition of diabetes, epilepsy and mental health changed slightly for 2006/07, and eleven new registers were introduced at that time: atrial fibrillation, chronic kidney disease, dementia, heart failure 1, heart failure 3, conditions assessed for depression, depression, learning disabilities, obesity, palliative care, and conditions assessed for smoking.

6.3 The cardiovascular disease – primary prevention register was introduced in 2009/10, the osteoporosis and peripheral arterial disease registers were introduced in 2012/13, and a rheumatoid arthritis register was introduced in 2013/14.

6.4 Two of the registers first included in the QOF for 2006/07, palliative care and conditions assessed for smoking, were redefined for 2008/09. The conditions assessed for smoking register was further amended for 2012/13.

6.5 The new diagnosis of depression register, depression 2, was renamed to depression 4 in 2011/12 but the register definition was unchanged. The register was amended in 2012/13 and renamed to depression 6; changes to the register meant it was no longer comparable to previous years. For 2013/14, the register was renamed, but no changes were made to the definition.

6.6 In 2013/14, the depression 1 register, conditions assessed for depression, was removed, and amendments were made to the hypothyroidism, mental health and heart failure due to LVSD registers.

6.7 In 2014/15, the hypothyroidism, chronic kidney disease and conditions assessed for smoking registers were removed, and there was a change to the definition of the cardiovascular disease – primary prevention register.

6.8 In 2015/16, the epilepsy, obesity, learning disabilities and peripheral arterial disease registers were removed.

6.9 There were no changes to the registers between 2016/17 and 2021/22.

6.10 In 2022/23, the depression, cardiovascular disease – primary prevention, osteoporosis and rheumatoid arthritis registers were removed. The chronic kidney disease register was re-introduced, having previously been removed in 2014/15. A new register for non-diabetic hyperglycaemia was also introduced in 2022/23.

6.11 There were no changes to the registers for 2023/24.

7. Register Definitions

(i) Active Registers

- **Asthma**: Number of patients with asthma, excluding those who have had no prescription for asthma-related drugs in the last 12 months.

- **Atrial Fibrillation**: Number of patients with atrial fibrillation.

- **Cancer**: Number of patients with a diagnosis of cancer, excluding non-melanotic skin cancers, from 1st April 2003.
    - Because of the date cut-off in the definition of this register, prevalence trends are obscured by the increase in the size of the register due to the cumulative accrual of new cancer cases onto practice registers with each passing year.

- **Coronary Heart Disease**: Number of patients with coronary heart disease.

- **Chronic Kidney Disease**: Number of patients aged 18 years and over with chronic kidney disease (categories G3a to G5). This register was removed from the QOF from 2014/15 and re-introduced in 2022/23.
    - This disease area applies to patients with category G3a, G3b, G4 and G5 CKD (eGFR<60 mL/min/1.73 m^2 confirmed with at least two separate readings over a three month period). Late presentation of patients with kidney failure increases morbidity, mortality and healthcare associated with costs.

- **Chronic Obstructive Pulmonary Disease (COPD):** Number of patients with chronic obstructive pulmonary disease.
    - In 2004/05 and 2005/06, QOF definitions did not allow patients to be on both asthma and COPD registers, thus patients with a degree of reversible airway disease were not included on the COPD register.
    - From 2006/07, the rules were revised to allow patients to be included on both COPD and asthma registers. Approximately 15% of patients with COPD will also have asthma. Any comparisons of COPD prevalence before and after this change in definition should be made with caution.

- **Dementia:** Number of patients diagnosed with dementia.
    - This register was introduced in April 2006 and there are no directly comparable statistics available for previous years.
    - This indicator applies to all people diagnosed with dementia either directly by the GP or through referral to secondary care.

- **Diabetes Mellitus:** Number of patients aged 17 years and over with diabetes mellitus, which specifies the type of diabetes where a diagnosis has been confirmed.
    - Since April 2006, the definition includes all patients aged 17 years and over with diabetes mellitus defined by clinical (Read) codes specific to Type 1 or Type 2 diabetes.

Previously there was a wider range of codes accepted under the definition, although the age constraint has remained consistent. The prevalence statistics for 2006/07 onwards are therefore not directly comparable with those for 2004/05 and 2005/06.

- In 2012/13, the register definition was expanded to include all diagnoses of diabetes as defined by the WHO (type I, type II, genetic, other and uncertain); previously the register only covered type I and type II. Gestational diabetes is excluded from the register.
- Although the practice must record whether the patient has Type 1, Type 2 or other diabetes, this level of detail is not collected centrally, therefore the register size cannot be disaggregated by type of diabetes.

- **Heart Failure:** Number of patients with heart failure.
  - Also known as Heart Failure 1.

- **Heart Failure due to LVSD:** Number of patients with a current diagnosis of heart failure due to left ventricular systolic dysfunction (LVSD).
  - Also known as Heart Failure 3.
  - The heart failure 3 register is a subset of the heart failure 1 register; all patients on the heart failure 3 register will also be included on the heart failure 1 register.
  - The Heart Failure 3 register originally included all patients with heart failure due to left ventricular dysfunction (LVD), from 2013/14 the definition was amended to include only patients diagnosed with left ventricular systolic dysfunction (LVSD), so the register is no longer comparable to previous years.

- **Hypertension:** Number of patients with established hypertension.

- **Mental Health:** Number of patients with schizophrenia, bipolar affective disorder, and other psychoses, and other patients on lithium therapy.
  - Since April 2006, the definition has included only patients with serious mental illness, defined as schizophrenia, bipolar affective disorder or other psychoses. Previously, patient selection was based on a more generalised set of mental health conditions and on the further condition that the patient required, and had consented to, regular follow-up. The prevalence statistics for 2006/07 to 2012/13 are therefore not directly comparable with those for 2004/05 and 2005/06. For 2013/14, the register definition was expanded to include other patients on lithium therapy, and the register is therefore no longer fully comparable with previous years.

- **Non-Diabetic Hyperglycaemia:** Number of patients aged 18 or over with a record of non-diabetic hyperglycaemia or pre-diabetes, which has not been superseded by a diagnosis of diabetes recorded prior to the beginning of the financial year.

- **Stroke and Transient Ischaemic Attack (STIA):** Number of patients with stroke or transient ischaemic attack (TIA).

(ii) Active Registers - not presented in "Raw Disease Prevalence in Northern Ireland" annual report or interactive dashboard.

- **Palliative Care:** Number of patients in need of palliative care/support, irrespective of age.
  - Prior to April 2008, the register applied only to patients aged 18 years and over. The age restriction was removed so that the register now includes patients of all ages. This means that the figures for 2008/09 onwards are not directly comparable with those for earlier years. Due to the nature of palliative care, patients may only be on the register for a short period of time. As a result, the practice palliative care register can only give an indication of the situation at the time the register was taken (prevalence day) and may not be a true reflection of practice prevalence throughout the rest of the year.

(iii) Inactive Registers

- **Cardiovascular Disease - Primary Prevention:** Percentage of patients with a new diagnosis of hypertension recorded in the preceding 1 April to 31 March (excluding those with pre-existing CHD, diabetes, stroke and/or TIA), who are aged 30 or over and who have not attained the age of 75, who have a CVD risk assessment score recorded in the preceding 15 months. This register was removed from the QOF from 2022/23.
  - This register was introduced in 2009/10 and counts those who are at risk of developing Cardiovascular Disease (CVD) so that this risk can be assessed. It is not a count of those with the condition.
  - The definition of the CVD - PP indicator refers to patients aged 30 - 74 years with a new diagnosis of hypertension (excluding those with pre-existing CHD or angina, diabetes, stroke and/or TIA, peripheral vascular disease, familial hypercholesterolemia, or CKD) in the previous year.
  - Until 2013/14 inclusive, the register was cumulative and included patients of all ages with a new diagnosis of hypertension since 1st April 2009. From 2014/15, this definition was changed to only include patients from April 2014; the register is now cumulative from April 2014.
  - Because of the date cut-off in the definition of this register, prevalence trends are obscured by the increase in the size of the register due to the cumulative accrual of new cases onto practice registers with each passing year.

- **Conditions assessed for depression**: Number of patients with diabetes and/or CHD. Formerly known as Depression 1. This register was removed from the QOF from 2013/14.
  - The register figures do not represent numbers of people with depression, but count people on the diabetes and/or CHD registers. The Depression 1 indicator then records whether patients with either or both of these conditions have been assessed for depression.

- **Conditions Assessed for Smoking:** Number of patients with any or any combination of the following conditions: coronary heart disease, PAD, stroke or TIA, hypertension, diabetes, COPD, CKD, asthma, schizophrenia, bipolar affective disorder or other psychoses; whose

notes record smoking status in the preceding 15 months. This register was removed from the QOF from 2014/15.

- The smoking indicator reports on whether smoking status has been recorded for patients with one or more of these conditions, but the actual smoking status is not collected centrally. The 'conditions assessed for smoking' register records the number of patients suffering from one or more of these conditions, but the prevalence of smoking among these patients cannot be derived.
- For 2006/07 and 2007/08 the register counted patients with any of the following conditions: CHD, stroke or TIA, hypertension, diabetes, COPD or asthma. In 2008/09, the definition of the register changed to include CKD, schizophrenia, bipolar affective disorder and other psychoses in addition to the conditions listed above. The prevalence figures for 2008/09 to 2012/13 are not comparable to those from earlier years because of the inclusion of these extra conditions. For 2013/14, PAD was added to the list of conditions, so the register was no longer fully comparable to previous years.

- **Depression**: Number of patients aged 18 years and over diagnosed with depression since April 2006. This register was removed from the QOF from 2022/23.
  - From 2006/07 to 2012/13, there were two different QOF registers and indicators related to depression, each based on different criteria. The first indicator relates to case finding of depression among patients with diabetes and/or Coronary Heart Disease (CHD). The second indicator relates to any patient newly diagnosed with depression since the preceding 1st April (e.g. for the 2010/11 QOF year, this would mean patients newly diagnosed after 1st April 2010). Both of the depression indicators were introduced to the QOF in April 2006 and there are no directly comparable statistics available for previous years in either case.
  - In 2012/13, a change was introduced to the technical business rules that exclude all patients identified prior to April 2006, which means that the latest figure is not comparable to previous years; the indicator was also renamed.
  - From 2013/14, only the newly diagnosed indicator is collected with QOF. The retired register counts patients with diabetes and/or CHD. The indicator measures whether patients with either or both of these conditions have been assessed for depression.
  - The remaining register for depression counts patients with newly diagnosed depression. The indicator then measures whether the severity of the depression has been assessed using an assessment tool validated for use in primary care.
  - An unusual feature has been noted within the technical business rules that define how clinical IT systems should count the register sizes for this indicator. Although the measurement of achievement against this indicator excludes patients diagnosed prior to the preceding 1st April (e.g. 1st April 2010 in the case of the 2011/12 QOF year), the pre-exclusion register size is used for prevalence purposes. For some practices with a long history of recording depression electronically in the clinical record (and where the depression is not recorded as having been resolved), a larger register size will be reported in comparison to an otherwise equivalent practice that has not been recording depression cases electronically over as long a time period.
  - The Depression register now has a date cut-off of April 2006, therefore increases in the register size will, at least in part, be due to the cumulative nature of the register.

- **Epilepsy:** Number of patients aged 18 years and over receiving drug treatment for epilepsy. This register was removed from the QOF from 2015/16.
    - Since April 2006, the definition of the register included patients aged 18 and over, whereas previously it included those 16 and over. The prevalence statistics for 2006/07 onwards are therefore not directly comparable with those for 2004/05 and 2005/06.

- **Hypothyroidism:** Number of patients with hypothyroidism who are currently treated with levothyroxine. This register was removed from the QOF from 2014/15.
    - Initially this register included all patients with established hypothyroidism, but from 2013/14 it was amended to exclude those who are not currently treated with levothyroxine so the register is no longer comparable to previous years.

- **Learning Disabilities:** Number of patients aged 18 years and over with learning disabilities. This register was removed from the QOF from 2015/16.

- **Obesity:** Number of patients aged 16 years and over with a Body Mass Index (BMI) greater than or equal to 30 recorded in the previous 15 months. This register was removed from the QOF from 2015/16.
    - Not all people who are obese are recorded as such by general practices, particularly if they are young and have not experienced any particular health-related difficulties. This register is prospective and as a result, apparent increases in prevalence may be due to improvement in recording and case finding by GPs, rather than a true increase in the prevalence in the population.

- **Osteoporosis:** Number of patients aged 50-74 years with a record of fragility fracture after 1 April 2012 and osteoporosis diagnosis confirmed on DXA scan, or those aged 75 years and over with a record of fragility fracture after 1 April 2012. This register was removed from the QOF from 2022/23.
    - As in the cancer register, because of the date cut-off in the definition of this register, prevalence trends are obscured by the increase in the size of the register due to the cumulative accrual of new cases onto practice registers with each passing year.

- **Peripheral Arterial Disease:** Number of patients with peripheral arterial disease. This register was removed from the QOF from 2015/16.

- **Rheumatoid Arthritis:** Number of patients aged 16 or over with rheumatoid arthritis. This register was removed from the QOF from 2022/23.

8. Further Information

For further information regarding GMS policy matters, contact:

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Where can I find information on QOF and Disease Prevalence across the UK?

England

Wales
The Quality Assurance and Improvement Framework (QAIF) was introduced in Wales as part of the contract reform in 2019; it replaced the Quality and Outcome Framework (QOF).

Scotland
QOF was removed from the GP contract in Scotland in April 2016. Disease Prevalence data is still available at the above link.

Note, the diseases/clinical areas included in QOF may differ across the UK. In addition, there may be definitional differences between countries for diseases/clinical areas.