

Virtual Diabetes Register: Technical Guide

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Contents

Guide for use statement	1
Possible reasons for false positives and false negatives	2
Change of clinical practice over time	2
Pharmaceuticals to treat diabetes and other conditions	3
Some methods for identifying people with diabetes lack specificity	3
References	3
2021 revision	4
2016 revision	5
Routine annual revision of the VDR	7
Privacy and confidentiality statement	8
Appendices	9
Appendix 1: Detailed information on VDR methodology (December 2022)	9
Appendix 2: Known data quality issues with the VDR	11
Appendix 3: Rule 8 of the Health Information Privacy Code 2020 and commentary	12
Appendix 4: Definitions of VDR variables	14
List of Tables	
Table 1: Summary of new variables introduced with output 2 of the VDR algorithm	4
Table 2: Changes to the VDR algorithm from March 2017	5

Guide for use statement

This document provides guidance about the appropriate use of the Virtual Diabetes Register (VDR) and highlights its limitations that users should be aware of.

Originally the VDR was designed to provide annual estimates of national diabetes prevalence and to inform policy and service planning. Since then, some of its outputs have also been used for statistical reporting and other research purposes.

After discussions with our legal advisors, Te Whatu Ora has concluded that districts and primary health organisations (PHOs) are entitled to request an identifiable copy of the VDR for the purposes of regional planning and/or undertaking a clinical audit. Specifically:

- a PHO is entitled to request information on patients enrolled at that PHO
- a district is entitled to request information on patients domiciled within that district **and** information on patients enrolled at PHOs it funds.

While the Te Whatu Ora will provide identifiable information to PHOs and districts in these circumstances, please note that the VDR was not designed to directly inform personal clinical intervention or action at an individual level. We do not recommend such practice. The VDR only identifies people within administrative data sets who have **suspected** diabetes based on the type of care they received in the past. The only diagnostic information used in creating the VDR is hospital clinical codes. For this reason, the VDR could potentially include people incorrectly identified as having diabetes when they do not.

The VDR collation process commences around the end of March each year and contains data from the previous calendar year up to 31 December. It identifies people with suspected diabetes from:

- hospital discharges coded for diabetes mellitus (DM)
- outpatient attendances for DM education management and DM retinal screening
- subsidised community dispensings of pharmaceutical therapies that people with diabetes typically use
- laboratory tests ordered where a patient has had four or more glycosylated haemoglobin (HbA1c) tests and two or more urinary albumin to creatinine ratio (ACR) tests.

Please see **Appendix 1** for further detail about the methodology, including the clinical codes used to identify diabetes mellitus within hospital events.

VDR estimates at an aggregate level have a high correlation with the numbers in the corresponding practice registers (e.g., Thornley et al 2011). At individual level, however, they include some false positives (individuals on the VDR who do not have diabetes) and false negatives (individuals not on the VDR who in fact have diabetes).

Possible reasons for false positives and false negatives

Reasons why the VDR may include false positives and false negatives include: clinical practice may change over time; pharmaceutical therapies for diabetes may be used to treat other conditions as well; and some methods of identifying people with diabetes may not exclude other conditions. Each of these reasons is illustrated here with an example. There are also variable degrees of data capture across districts as noted in Appendix 2.

Change of clinical practice over time

Example: HbA1c testing

The actual results of HbA1c tests are not available to confirm the diagnosis of diabetes, and the VDR algorithm relies on the fact that a given number of HbA1c tests were completed. However, HbA1c tests could be carried out for other purposes, such as screening for diabetes, or monitoring people with pre-diabetes or gestational diabetes.

The potential for incorrect identification has increased recently as the use of HbA1c in screening has become more common over time. This greater use may in part be a result of the formal endorsement of HbA1c as one of the diagnostic tests for the diagnosis of diabetes. Another reason why screening for diabetes has increased over time is that it is part of the cardiovascular (CVD) risk assessment, which itself has become more common as one of the national health targets.

The VDR attempts to address this potential source of error by using a strict selection criterion within the laboratory test part of the code. Specifically, to be on the VDR a person must have four or more HbA1c tests as well as two or more ACR tests within a two-year period.

Pharmaceuticals to treat diabetes and other conditions

Example: Metformin

The VDR collects data on the dispensing of metformin as a pharmaceutical used to treat diabetes but it may also be used to treat a range of conditions other than diabetes, including pre-diabetes, polycystic ovarian syndrome and gestational diabetes. The VDR attempts to partially address this issue by excluding women aged 12–45 years who are **solely** identified as a result of metformin use – that is, no other methods identify them as having diabetes.

Some methods for identifying people with diabetes lack specificity

Example: Outpatient data

The VDR uses outpatient data to identify people with suspected diabetes based on the type of outpatient clinic a person attended, rather than the diagnosis made in the clinic.

In the past, when the VDR was used solely at an aggregated or de-identified level, the impact of data quality issues has been small because the false positives and false negatives cancel each other out to a certain extent. However, using the VDR at an individual level increases the risk that the false positives (around 18 percent) and negatives (2 percent) will have a more harmful impact. For example, a health service might contact a patient without diabetes as part of diabetes clinical intervention or action.

A study of data for the Auckland Metro area from 31 December 2014 indicates that the revised VDR algorithm has a specificity of around 97 percent, sensitivity of around 87 percent, positive predictive value of 82 percent and negative predictive value of 98 percent (Chan et al 2018).

References

Chan WC, Papaconstantinou D, Lee M, et al. 2018. Can administrative health utilisation data provide an accurate diabetes prevalence estimate for a geographical region? *Diabetes Research and Clinical Practice* 139: 59–71.

Thornley S, Wright C, Marshall R, et al. 2011. Can the prevalence of diagnosed diabetes be estimated from linked national health records? The validity of a method applied in New Zealand. *Journal of Primary Health Care* 3(4): 262–8.

2021 revision

In 2021, a more inclusive version of the VDR algorithm was established in addition to the traditional version. This enables the VDR to support a wider range of analyses.

- **Output 1 (traditional method)** bases the diabetes prevalence estimates solely on the number of people alive and enrolled in a PHO **at 31 December of the VDR year**. This output method is useful for the purposes of health service planning, for example. The latest version of the VDR is v689.
- **Output 2 (more inclusive version)** bases the diabetes prevalence estimates on people who were alive and enrolled in a PHO **at some point during the calendar year** (see Table 1). This version can be used to:
 - better capture the population of people living with diabetes over the year of interest. This would be a useful output method when considering the cost and/or burden of disease over a year, for example.
 - include people that have died during the year. This allows more representative reporting of some outcomes, such as amputation rates for people with diabetes, and potentially other diabetes-related complications.

The updated VDR algorithm allows for the use of either of these methods of calculating diabetes prevalence. The tables presented on the Te Whatu Ora website contain data using output 1 of the VDR. If the user prefers to include people who were alive, those that have died, and PHO enrolled at any point during the year (output 2), this data is available to download also. For additional variables, you can make data requests to data-enquiries@health.govt.nz. See **Appendix 4** for a full list of VDR variables.

Table 1: Summary of new variables introduced with output 2 of the VDR algorithm

New variable	Summary of change
PHO_Enrolled_in_year	Indicates if an individual has been enrolled in a PHO at any point during the calendar year.
Month_yr_of_death	If an individual was alive at any point during the calendar year, the value in this column will equal month and year of death.

The changes detailed above will be applied to the VDR and, in order to keep a consistent time series, historical versions of the VDR have been re-extracted using the updated algorithm.

For further information or if you want updated VDR data please contact data-enquiries@health.govt.nz.

2016 revision

In 2016, the VDR algorithm was updated to improve its accuracy in estimating diabetes prevalence. The changes came into effect in March 2017.

Specifically, we compared assigned diabetes status of individuals based on the 2014 version of the VDR with the diabetes status based on the laboratory results stored in the Auckland regional laboratory result repository (TestSafe). We then refined the existing VDR algorithm by reviewing the sensitivity and positive predictive value of the VDR algorithm rules both individually and in combination. Table 2 summarises the changes based on this work.

Table 2: Changes to the VDR algorithm from March 2017

Change	Summary of change	Example of change
Reduced the time period of outpatient data (NNPAC) queried.	Three years of outpatient data is now queried to look for any evidence of diabetes (retinal screening or DM outpatient events). Previously all outpatient data (from July 2002 onwards) was considered for inclusion.	Old algorithm: Include if relevant outpatient event occurred between July 2002 and 2016. 2017 algorithm: Include if relevant outpatient event occurred between 2014 and 2016.
Reduced the time period of inpatient data (NMDS) queried.	Ten years of inpatient data is now queried to look for any evidence of diabetes (coded diagnoses). Previously all inpatient data (from 1999 onwards) was considered for inclusion.	Old algorithm: Include if relevant publicly funded discharge occurred between 1999 and 2016. 2017 algorithm: Include if relevant inpatient event occurred between 2007 and 2016.
Removed unnecessary data conditions from the pharmaceutical and outpatient parts of the algorithm.	Pharmaceuticals: Dispensings of glucagon are no longer considered as evidence of diabetes as people with diabetes-dispensed glucagon will also be dispensed other diabetes-related pharmaceuticals. Outpatient: The diabetes specialist/endocrinology clinics attendance rule was removed because it was also redundant. That is, to be included under this condition, a person would also need to meet another data condition.	Old algorithm: Include if person received two or more dispensings of glucagon hydrochloride (1570); include if person attended specialist/endocrinology clinic (purchase unit codes of M20004 and M20005) and also meets one of the other criteria. 2017 algorithm: These data conditions are no longer used.

Change	Summary of change	Example of change
Refined the algorithm so that it does not unintentionally include women receiving screening tests or treatment related to gestational diabetes. More specifically pharmaceuticals and lab tests around birth are not considered for inclusion.	Insulin may be used to treat gestational diabetes and a high number of lab tests are ordered for people with this condition. For this reason, insulin dispensed within five months before and three weeks after a birth event are not used in compiling the VDR. Likewise, lab tests with a visit date between nine months before and the day of the birth are not considered for inclusion.	New: This is a newly introduced data condition. Note: Metformin is also known to treat gestational diabetes, among other conditions. The previous version of the VDR algorithm already accounts for this by not considering for inclusion women aged 12–45 who are dispensed metformin.
Added more requirements for identification within the laboratory claim data to limit false positives related to diabetes screening.	To be included on the VDR, a person must have four or more HbA1c tests and two or more ACR tests within a two-year period. Previously a person needed four HbA1c tests and one ACR test.	Old algorithm: Include if a person had four or more HbA1c (lab test code BG2) and one ACR (lab test code BP8) tests between 2015 and 2016. 2017 algorithm: Include if a person had four or more HbA1c (lab test code BG2) and two ACR (lab test code BP8) tests between 2015 and 2016.

Note: ACR = urinary albumin to creatinine ratio; DM = diabetes mellitus; HbA1c = glycosylated haemoglobin; NMDS = National Minimum Dataset (inpatients); NNPAAC = National Non-Admitted Patient Collection (outpatients).

Routine annual revision of the VDR

The newly subsidized medications for diabetes, such as Vildagliptin, Empagliflozin, and Dulaglutide, Liraglutide have been incorporated into the VDR algorithm at the time the subsidy was implemented. New variables covering SGLT2i and GLP1RA are added given there are likely research and policy interest in the uptake of these medicines.

Privacy and confidentiality statement

Data users should be aware of their responsibilities for protecting patient confidentiality under the provisions of the Privacy Act 2020 and the Health Information Privacy Code 2020. For Rule 8 of the Code and a commentary on it, see **Appendix 3**.

Only use the VDR data set internally within your organisation and do not make it available to any other party without our prior consent.

The only exceptions are when you are disseminating summary data through research documents and/or statistical publications. It is then the responsibility of the author(s) of any publications to ensure that information is not published in a manner that could reasonably be expected to identify any individual concerned.

Data users are responsible for ensuring your computer systems are suitable to securely store any information supplied. For a guide on storage, security, retention and disposal of health information, see <https://www.privacy.org.nz/privacy-act-2020/privacy-principles/>.

Data users should make no attempt to link identifiable information with de-identified information (and vice versa). Identifiable data includes, but is not limited to, NHI number, name and address.

Appendices

Appendix 1: Detailed information on VDR methodology (December 2022)

The VDR counts individuals who had any of the following.

1. Publicly funded hospital discharges between 2013 and 2022, with any of the following diagnosis codes (ICD-10-AM version 6):
 - E10 – Type 1 diabetes mellitus
 - E11 – Type 2 diabetes mellitus
 - E12 – Malnutrition-related diabetes mellitus
 - E13 – Other specified diabetes mellitus
 - E14 – Unspecified diabetes mellitus
 - O240 – Pre-existing diabetes mellitus, Type 1, in pregnancy
 - O241 – Pre-existing diabetes mellitus, Type 2, in pregnancy
 - O242 – Pre-existing diabetes mellitus, other specified type, in pregnancy
 - O243 – Pre-existing diabetes mellitus, unspecified, in pregnancy

Note: Admissions with a code for gestational diabetes are not included.
2. Diabetes 'education and management' (purchase unit code of M20006) or diabetes retinal (fundus) screening (purchase unit code of M20007) within the outpatient collection (NNPAC) between 2020 and 2022.
3. Publicly funded pharmaceuticals dispensed within the community on two or more occasions between 2021 and 2022. Pharmaceuticals with the following chemical IDs are included:
 - 1192 Insulin lispro
 - 1247 Acarbose
 - 1567 Glibenclamide
 - 1568 Gliclazide
 - 1569 Glipizide
 - 1570 Glucagon hydrochloride
 - 1648 Insulin neutral
 - 1649 Insulin isophane
 - 1655 Insulin zinc suspension
 - 1794 Metformin hydrochloride

- 2276 Tolazamide
- 2277 Tolbutamide
- 3739 Rosiglitazone
- 3783 Insulin aspart
- 3800 Pioglitazone
- 3857 Insulin glargine
- 3882 Insulin lispro with insulin lispro protamine
- 3908 Insulin glulisine
- 3982 Insulin aspart with insulin aspart protamine
- 4103 Vildagliptin
- 4104 Vildagliptin with metformin hydrochloride
- 4137 Empagliflozin
- 4138 Empagliflozin with metformin hydrochloride
- 4149 Dulaglutide
- 6300 Insulin isophane with insulin neutral
- 4173 Liraglutide

Note: Metformin is also used to treat polycystic ovary syndrome in women aged 12–45 years. Women who are dispensed metformin within this age group have not been included within the VDR. Likewise, because insulin is also used to treat gestational diabetes, women dispensed insulin within 5 months before and two weeks after the birth discharge date of the birth event have not been included.

4. Four or more HbA1c, glycosylated haemoglobin lab tests (lab test code BG2) and two or more ACR tests (lab test code BP8) between 2021 and 2022.

Note: To avoid unintentionally including people with gestational diabetes, the VDR does not include women who had lab HbA1c tests within 9 months before the birth event.

Appendix 2: Known data quality issues with the VDR

Some of the source data that informs the VDR has not been consistently reported across all the districts in New Zealand. A number of data gaps are likely to affect the accuracy of the VDR (in particular with sensitivity/coverage). Apply caution when interpreting any analyses based on the VDR on a regional level.

Districts	Data sources	Known missing data
021 Waitematā	NNPAC	Purchase unit M20006 not reported from January 2019 to March 2020 Purchase unit M20007 volumes lower than expected from July 2022 to Dec 2022
022 Auckland	NNPAC	Missing M20006 volumes between January 2018 to June 2019
042 Lakes	NNPAC	Purchase unit M20007 data not reported
047 Bay of Plenty	NNPAC	Purchase unit M20006 and M20007 data not reported
051 Tairāwhiti	Community lab claims data	Missing lab claims data from Oct 2021 to August 22, and October 2022
071 Hawke's Bay	NNPAC	Purchase unit M20007 data not reported
081 MidCentral	NNPAC	Purchase unit M20007 data not reported
	Community lab claims data	Missing lab claims data from May 2022 to December 2022
082 Whanganui	Community lab claims data	Missing lab claims data from May 2022 to December 2022
091 Capital & Coast	NNPAC	No volumes reported between December 2018 and March 2020, for purchase unit M20007 reported
092 Hutt Valley	NNPAC	Purchase unit M20007 data not reported
093 Wairarapa	NNPAC	Purchase unit M20007 data not reported
111 West Coast	NNPAC	Purchase unit M20007 data not reported
	Community lab claims data	Some diabetes-related test volumes missing
120 Canterbury	Community lab claims data	Some diabetes-related test volumes missing
160 Southern	NNPAC	Purchase unit M20007 volumes lower than expected from August 2022 to November 2022

In 2020, the level of diabetes health service activities decreased due to the response to COVID-19 (with a reduction in service utilisation during the lockdown). This may also have affected the accuracy of the VDR.

Appendix 3: Rule 8 of the Health Information Privacy Code 2020 and commentary

Rule 8: Accuracy etc of health information to be checked before use or disclosure

1. A health agency that holds health information must not use or disclose that information without taking any steps that are, in the circumstances, reasonable to ensure that the information is accurate, up to date, complete, relevant and not misleading.
2. This rule applies to health information obtained before or after the commencement of this code.

Commentary

Rule 8 aims to protect individuals by requiring agencies that hold health information to check its accuracy before using it. What checking an agency must do will vary depending on matters such as:

- the proposed use of the information
- the age of the information and the reliability of its source
- the practicalities of verifying accuracy or currency
- the probability, severity and extent of potential harm for the individual if the information is inaccurate.

Purpose of using the information

The steps that it is reasonable to take to check information will vary depending on the proposed use. If the user is going to aggregate the information for statistical purposes, they may need to do only a few or no checks, particularly if the checking process would unnecessarily intrude on the individual's privacy. By contrast, rigorous checks will be appropriate if decisions on health care entitlements or treatment alternatives are to be based on that information.

Accuracy and completeness of information collected directly

It is important to have accurate health information for all the purposes it is used for – care and treatment, administration, monitoring quality of care, training and education. Reasonable steps for ensuring accuracy might include:

- having individuals check the accuracy of the health information they supply at the time it is collected
- informing individuals of their own responsibility to keep their name and address information up to date
- where information is computerised, adopting a data outlier program to identify when data falls outside expected ranges and values
- training staff appropriately.

Accuracy and completeness of information from another health agency

It may be more difficult for health agencies to ensure accuracy and completeness of information they receive from another health agency, rather than collected it directly from individuals. If the information is going to be used, agencies dealing directly with the individual concerned should check the accuracy of the information with the individual at an early opportunity, if practicable. Also consider recording the source of the information on the file.

Keeping information up to date

In developing procedures to update health information, health agencies need to consider whether:

- the individual might be harmed if the information is out of date
- treatment might be affected if the information is out of date
- disclosing updated information to a health agency that is permitted to receive it might lead the agency to treat the individual differently.

Agencies should check information that is likely to change, such as an address – perhaps at each encounter with the individual.

Appendix 4: Definitions of VDR variables

Variable	Description	Source
DM inpatient (count of events)	The number of publicly funded hospitalisation discharges that contain any diagnosis related to diabetes (E10, E11, E13, E14, O240, O241, O242, O243, ICD-10-AM-VI)	NMDS
Diabetes management clinic (count of events)	The number of outpatient events that contain an education management purchase unit code (M20006)	NNPAC
Diabetes retinal screening (count of events)	The number of outpatient events that contain a diabetes retinal screening purchase unit code (M20007)	NNPAC
DM retinal screening in last 2 years (count of events)	The number of outpatient events that contain a diabetes retinal screening purchase unit code (M20007) with a date of service in the time period	NNPAC
DM pharm dispense (count of events)	The number of pharmaceutical dispensings for the chemical IDs listed in step five (chemical ID = 1192, 1247, 1567, 1568, 1569, 1648, 1649, 1655, 1794, 2276, 2277, 3739, 3783, 3800, 3857, 3882, 3908, 3982, 6300, 4103, 4104, 4137, 4138, 4149, 4173)	Pharms
DM pharm metformin (count of events)	The number of pharmaceutical dispensings where the chemical ID = 1794, 4104, 4138	Pharms
DM pharm insulin (count of events)	The number of pharmaceutical dispensings where the chemical ID = 1192, 1648, 1649, 1655, 3783, 3857, 3882, 3908, 3982, 6300	Pharms
DM pharm sulfonylurea (count of events)	The number of pharmaceutical dispensings where the chemical ID = 1567, 1568, 1569, 2276, 2277	Pharms
DM pharm sensitiser (count of events)	The number of pharmaceutical dispensings where the chemical ID = 3739, 3800	Pharms
DM pharm SGLT2i (count of events)	The number of pharmaceutical dispensings where the chemical ID = 4137, 4138	Pharms
DM pharm GLP1RA (count of events)	The number of pharmaceutical dispensings where the chemical ID = 4149, and 4173	Pharms
DM pharm other (count of events)	The number of pharmaceutical dispensings where the chemical ID = 1247, 4103, 4104	Pharms
LAB HBA1C (count of events)	The number of laboratory tests where the lab test code = BG2	Labs
LAB ACR (count of events)	The number of laboratory tests where the lab test code = BP8	Labs
Practice name	PHO practice name	PHO enrolment
PHO name	PHO name	PHO enrolment
PHO ID	PHO identifier	PHO enrolment
PRACTICE ID	PHO practice identifier	PHO enrolment

Variable	Description	Source
Lead DHB	DHB of service: The district responsible for contracting the PHO	PHO enrolment
PHO	Where the person is enrolled at a PHO during the quarter, show 'PHO_Enrolled'; otherwise show null	PHO enrolment
PHO enrolled in year	Indicates if an individual has been enrolled in a PHO at any point during the calendar year	PHO enrolment
Date of birth	Date of birth of person	NHI
Date of death	Date of death. If not died, will be missing	NHI
Gender	Gender	NHI
Ethnicity 1	Ethnicity code 1. Level 2 ethnicity	NHI
Ethnicity 2	Ethnicity code 2. Level 2 ethnicity	NHI
Ethnicity 3	Ethnicity code 3. Level 2 ethnicity	NHI
Prioritised ethnicity group	Ethnicity is prioritised in the order: Māori, Pacific, Asian, MELAA, European, Other	NHI
Domicile code	Domicile code from the person's address of residence	NHI
NZ Dep06	Mapped from the domicile code on the NHI	NHI
NZ Dep13	Mapped from the domicile code on the NHI	NHI
NZ Dep 18	Mapped from the domicile code on the NHI	NHI
Month yr of death	If an individual was alive at any point during the calendar year, the value in this column will equal month and year of death	NHI
DOMDHBN	The district of domicile code mapped from the domicile code from the domicile address on the NHI	NHI
Age	Calculated as at 31 December of the relevant year, based on date of birth from NHI	NHI
Inpatient first identification date	The admission date of the first publicly funded diabetes-related hospitalisation event (any diagnosis of E10, E11, E13, E14, O240, O241, O242, O243)	NMDS
Inpatient last identification date	The admission date of the last publicly funded diabetes-related hospitalisation event (any diagnosis of E10, E11, E13, E14, O240, O241, O242, O243)	NMDS
Outpatient first identification date	The date of service of the first diabetes-related outpatient event (purchase unit code = M20006, M20007)	NNPAC
Outpatient last identification date	The date of service of the last diabetes-related outpatient event (purchase unit code = M20006, M20007)	NNPAC
Pharm first identification date	The dispense date of the first diabetes-related dispensing (chemical ID = 1192, 1247, 1567, 1568, 1569, 1648, 1649, 1655, 1794, 2276, 2277, 3739, 3783, 3800, 3857, 3882, 3908, 3982, 6300, 4103, 4104, 4137, 4138, 4149, 4173)	Pharms

Variable	Description	Source
Pharm last identification date	The dispense date of the last diabetes-related dispensing (chemical ID = 1192, 1247, 1567, 1568, 1569, 1648, 1649, 1655, 1794, 2276, 2277, 3739, 3783, 3800, 3857, 3882, 3908, 3982, 6300, 4103, 4104, 4137, 4138, 4149, 4173)	Pharms
Lab first identification date	The lab visit date of the first HbA1c or ACR test (lab test code = BG2, BP8)	Labs
Lab last identification date	The lab visit date of the last HbA1c or ACR test (lab test code = BG2, BP8)	Labs
First identification date	The first date out of the inpatient, outpatient, Pharms and Labs dates listed above	
DM related traces	Summary of which collections events found in (Inpatient, Outpatient, Pharms, Lab)	
Ethnic name4	Ethnicity grouped into European/Other, Māori, Pacific people, Indian	NHI
Ethnicity MnM	Ethnicity grouped into Māori or non-Māori	NHI
Age group	Five-year age group	NHI
DOMDHB_name	District of domicile name (mapped from the domicile code on the NHI)	NHI
Live	Show live if person is alive as at 31 December of the VDR year, ie, for VDR2021 DOD is null or greater than 31/12/2021	NHI
Year	VDR year	
Count_VDR (count of people)	Count of people on the VDR	

Note: DHB = district health board. Districts are defined by former DHB boundaries ; DM = diabetes mellitus; MELAA = Middle Eastern, Latin American, African; NHI = National Health Index; NMDS = National Minimum Dataset (inpatients); NNPAAC = National Non-Admitted Patient Collection (outpatients); Pharms = Pharmaceutical Collection; PHO = primary health organisation.