INTRODUCTION
To reduce the high impact of chronic diseases, disease management programmes (DMPs) have been introduced in primary care in countries such as Germany, Sweden, the UK, the US, and the Netherlands.1 DMPs are multidisciplinary efforts to improve the quality and efficiency of chronic disease management by providing continuous, patient-centred, comprehensive care.2,3 DMPs encompass the management of patients with high-impact chronic diseases, such as cardiovascular disease (CVD), diabetes mellitus, or chronic obstructive pulmonary disease (COPD).4 In the Netherlands, chronic disease care is regionally coordinated by general practice care groups that share responsibility for delivering DMPs to their patients. Quality of care is assured by developing DMPs in line with national disease monitoring standards and by benchmarking practices’ performance against national criteria,4 thereby potentially preventing deterioration and complications in chronic diseases while maintaining a high quality of life.5,6

For some patient groups, such as patients with intellectual disabilities (ID), reducing the impact of chronic diseases is more complex. Although around 1%-1.5% of people globally are diagnosed with ID, the actual prevalence is likely to be higher, as not all IDs are recognised in general practice.1 People with ID experience significant limitations in intellectual functioning and adaptive behaviour, often manifested as difficulties recognising disease symptoms and understanding disease consequences, and, consequently, have increased health needs and health problems compared with people without ID.8-12 People with ID therefore have to avail of care more than people without ID.8,14 Moreover, chronic diseases such as CVD, diabetes mellitus, and COPD are more prevalent among people with ID, develop at younger ages, and occur more often in males with ID than in females with ID.13 These differences are seldom addressed in existing literature, disease guidelines, or DMPs.14

Despite these distinct characteristics, chronic disease management for patients with ID is provided mostly within the non-ID-oriented setting of general practice, which can be challenging for GPs. GPs have expressed difficulties in providing care to patients with ID, mostly relating to communication, continuity of care, and time constraints.17 These difficulties are reflected in compliance with guidelines. Although previous studies do not take DMP enrolment into account, most show that routine examinations advocated in DMPs are provided less frequently for patients with than without ID.18-21 Non-compliance with protocols and guidelines not only compromises quality of care, but may also contribute to health disparities, and puts patients with both chronic illness and ID at increased risk of complications, avoidable

M van den Bemd (ORCID: 0000-0002-0971-3029), MSc, PhD candidate; M Cuypers (ORCID: 0000-0003-1715-4375), PhD, senior researcher; BWM Schalk (ORCID: 0000-0002-4259-1715), PhD, senior researcher; GL Leusink (ORCID: 0000-0003-2944-1110), MD, PhD, professor; EWMA Bischoff (ORCID: 0000-0002-3323-8475), MD, PhD, GP and researcher, Department of Primary and Community Care, Radboud University Medical Centre, Nijmegen, the Netherlands.

Correspondence
Milou van den Bemd, Department of Primary and Community Care, Radboud University Medical Centre, Geer Grooteplein zuid 10, 6525 GA Nijmegen, the Netherlands.

Email: milou.vandenbemd@radboudumc.nl

Submitted: 13 January 2023; Editor’s response: 28 February 2023; final acceptance: 12 May 2023.

©The Authors
This is the full-length article (published online 5 Sep 2023) of an abridged version published in print. Cite this version as: Br J Gen Pract 2023; DOI: https://doi.org/10.3399/BJGP.2023.0029
hospital admissions, and even premature mortality.25,26

To tackle these inequalities, it is essential to strengthen the evidence base for providing adequate, suitable care for patients with chronic illness and with ID. Although enrolment in DMPs was similar for patients with chronic illness with and without ID, those with ID who were not enrolled received routine examinations less often and received medication prescriptions more often. Most patients with and without ID enrolled in DMPs received routine examinations at similar high frequencies. Although DMPs do not specifically address the needs of patients with both chronic illness and ID, these patients do not seem underserved in the management of chronic diseases in terms of consultation, medication, and tests.

How this fits in

Because of the different chronic disease patterns and care needs of people with intellectual disabilities (ID), providing such patients with suitable chronic disease care within non-ID-oriented disease management programmes (DMPs) in primary care may be challenging. Although enrolment in DMPs was similar for patients with chronic illness with and without ID, those with ID who were not enrolled received routine examinations less often and received medication prescriptions more often. Most patients with and without ID enrolled in DMPs received routine examinations at similar high frequencies. Although DMPs do not specifically address the needs of patients with both chronic illness and ID, these patients do not seem underserved in the management of chronic diseases in terms of consultation, medication, and tests.

Study groups

For patients with a CVD, diabetes mellitus, or COPD diagnosis, data were collected retrospectively from 2015 onwards, or from diagnosis onwards. Patients with ID were identified by the presence of ICPC code P85 ‘Mental retardation’ in their medical record or when ID indicators were found through data linkage with ID-related social support or long-term care.7 Selecting all adults (aged ≥18 years) with ID and a chronic disease, the authors matched them randomly to five people without ID indicators in the same 10-year age group, of the same sex, and with the same chronic disease.

Operationalisations

Patients were coded as being enrolled in a DMP if they had a record of enrolment in a DMP, if their GP was being coded as the main provider for chronic illness, or when >75% of the indicators, as advised in the DMP care guidelines, were fulfilled (see Supplementary Figure S1).31 Patients with solely a CVD diagnosis could be admitted to the CVD-DMP, patients with diabetes mellitus (with or without CVD or COPD) to the diabetes mellitus-DMP, and patients with COPD (with or without CVD or diabetes mellitus) to the COPD-DMP.

To examine disease monitoring, first consultations and medication prescriptions were examined. The mean of all consultations between 2015 and 2018 for all patients with CVD, diabetes mellitus, and COPD were calculated separately (weighted by patients’ registration time in general practice). The average (weighted) number of consultations (9.1 consultations per year for CVD, 8.3 for diabetes mellitus, and 9.3 for COPD) was used as the cut-off point to distinguish between individuals who were less and more ‘frequent consulters’. Similar calculations were used for medications based on prescriptions for CVD, diabetes mellitus, or COPD. The average (weighted) number of prescriptions between 2015 and 2018 for all patients with CVD, diabetes mellitus, or COPD (1.8 prescriptions per year) was used as the cut-off point to distinguish between less and more frequent users.

Second, frequency of key routine examinations in 2018 were examined. Several indicators considered essential for the monitoring of chronic disease according to Dutch and international guidelines were found.4,21,32,33 For CVD, these were the presence of a record of low-density lipoprotein (LDL) measurement for those aged <80 years and of a blood pressure test. For diabetes mellitus, these were presence of a record of haemoglobin A1C (HbA1c)
Table 1. Descriptive statistics of patients with and without intellectual disabilities with chronic diseases

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients with ID, n (%)</th>
<th>Control group, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>2653</td>
<td>13 265</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>1519 (57.3)</td>
<td>7595 (57.3)</td>
</tr>
<tr>
<td>Females</td>
<td>1134 (42.7)</td>
<td>5670 (42.7)</td>
</tr>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–30</td>
<td>193 (7.3)</td>
<td>965 (7.3)</td>
</tr>
<tr>
<td>31–50</td>
<td>644 (24.3)</td>
<td>3220 (24.3)</td>
</tr>
<tr>
<td>51–70</td>
<td>1533 (58.5)</td>
<td>7765 (58.5)</td>
</tr>
<tr>
<td>≥71</td>
<td>243 (9.9)</td>
<td>1315 (9.9)</td>
</tr>
<tr>
<td>Registration time at GP, years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤1</td>
<td>370 (13.9)</td>
<td>1751 (13.2)</td>
</tr>
<tr>
<td>1.1–2</td>
<td>468 (17.6)</td>
<td>2834 (21.4)</td>
</tr>
<tr>
<td>2.1–3</td>
<td>169 (6.4)</td>
<td>819 (6.2)</td>
</tr>
<tr>
<td>3.1–4</td>
<td>1646 (62.0)</td>
<td>7861 (59.3)</td>
</tr>
<tr>
<td>Diagnosis of chronic disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CVD</td>
<td>845 (31.9)</td>
<td>4228 (31.9)</td>
</tr>
<tr>
<td>Indication for CVD-DMP</td>
<td>593 (70.2)</td>
<td>2952 (69.8)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>1584 (59.7)</td>
<td>7575 (57.1)</td>
</tr>
<tr>
<td>Indication for diabetes mellitus-DMP</td>
<td>1584 (100.0)</td>
<td>7575 (100.0)</td>
</tr>
<tr>
<td>COPD</td>
<td>736 (27.7)</td>
<td>3680 (27.7)</td>
</tr>
<tr>
<td>Indication for COPD-DMP</td>
<td>736 (100.0)</td>
<td>3680 (100.0)</td>
</tr>
</tbody>
</table>

≤ Unless otherwise stated. ≥ Prevalence of chronic diseases is estimated with diagnoses in medical records based on International Classification of Primary Care codes. If patients had diabetes mellitus as well as CVD, they were admitted to diabetes mellitus-DMP. All patients with a diagnosis of COPD had an indication for the COPD-DMP. COPD = chronic obstructive pulmonary disease. CVD = cardiovascular disease. DMP = disease management programmes. ID = intellectual disabilities. SD = standard deviation.

RESULTS

Demographics

Patients with ID and at least one chronic illness (n = 2653) were identified and matched with 13 265 controls without ID (Table 1). Most patients with and without ID were male (57.3%) and aged between 51 and 70 years (58.5%). Most patients with ID had a diagnosis of diabetes mellitus (59.7%, n = 1584), followed by CVD (31.9%, n = 845), and COPD (27.7%, n = 736). Of patients with ID, 62.0% (n = 1646) were registered 3.1–4 years at the GP compared with 59.3% (n = 7861) of controls. Of patients with ID, 70.2% (n = 593) had an indication for CVD-DMP, compared with 69.8% (n = 2952) of controls.

Enrolment in DMPs

Enrolment of people with ID in DMPs for CVD (43.8%) and COPD (41.0%) was comparable and not statistically significantly different from controls (Figure 1). Patients with diabetes mellitus and ID were more likely to be enrolled in a DMP than controls (69.8% versus 62.6%, OR 1.44, 95% CI = 1.27 to 1.64; Supplementary Table S2) and received diabetes mellitus care in specialist care settings less often than their controls (4.9% versus 7.0%, OR 0.65, 95% CI = 0.51 to 0.84).

Disease monitoring

For those enrolled in DMPs, patients with chronic illness and ID were more likely than their controls to be frequent consulters: that is, for patients with ID and CVD (OR 2.71, 95% CI = 1.91 to 3.84), diabetes mellitus (OR 2.49, 95% CI = 2.14 to 2.89), and COPD (OR 3.01, 95% CI = 2.18 to 4.16; Table 2). Similar results were found for those not enrolled in DMPs.

On average, between 2015 and 2018, patients with CVD, diabetes mellitus, and COPD received 1.8 prescriptions per year. Only among those not enrolled in DMPs were differences observed in frequency of medication prescriptions: patients with ID and diabetes mellitus (OR 1.46, 95% CI = 1.10 to 1.95) or patients with ID and COPD (OR = 1.28, 95% CI = 0.99 to 1.66) were more likely to receive >1.8 prescriptions per year than their controls (Table 2).

In those enrolled in CVD-DMP, there were no significant differences between patients with ID and their controls in the frequency of LDL checks (92.0% versus 92.3%) and blood pressure tests (78.8% versus 78.0%). In those not enrolled in CVD-DMP, patients with ID had a lower likelihood (30.1%) than their controls (41.1%; OR 0.60, 95% CI = 0.42 to 0.87) of receiving an LDL check (Table 2).
HbA1c was more likely to be measured in patients with diabetes mellitus and ID who were not enrolled in the DMP (36.8%) than their controls (24.8%; OR 1.85, 95% CI = 1.34 to 2.55; Table 2).

In patients with COPD with and without ID who were enrolled in COPD-DMP, occurrence of receiving ≥2 prescriptions of inhalation medication (79.1% and 79.2%) and discussing smoking behaviour with care providers (80.5% and 78.1%) was similar. Patients with COPD and ID who were not enrolled in COPD-DMP were more likely to receive ≥2 prescriptions of inhalation medication (80.8%) than their controls (69.5%; OR 1.84, 95% CI = 1.32 to 2.57, Table 2).

DISCUSSION

Summary

This study compared enrolment in DMPs and disease monitoring for chronically ill patients with ID and their controls. Only patients with both diabetes mellitus and ID were more often enrolled in DMPs. Patients with ID enrolled in CVD-DMP, diabetes mellitus-DMP, or COPD-DMP received consultations more often than their enrolled controls. Among those not enrolled in a DMP, patients with ID received consultations, medication prescriptions, and routine examinations (apart from LDL measurement) more often than their controls. Despite the frequently reported care inequities between people with and without ID, the current study did not find evidence for limited access to DMPs for patients with an ID diagnosis and a chronic disease. Additional research is needed to explore whether chronic disease care meets the needs of this complex patient population.

Strengths and limitations

This study is the first, to the authors’ knowledge, to examine DMP enrolment and disease monitoring for patients with ID and their controls by DMP enrolment using large-scale, individual-level data from a population-based primary care database. By linking datasets and using multiple methods to identify people with ID, the common problem of underreporting ID in medical records was reduced and...
Table 2. Frequency and percentage of patients with chronic illness with and without intellectual disabilities, on disease monitoring within and outside disease management programmes in 2015–2018a

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Enrolled in DMP, n (%)</th>
<th>Conditional OR (95% CI)</th>
<th>Not enrolled in DMP, n (%)</th>
<th>Conditional OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVD</td>
<td>Patients with ID</td>
<td>Controls</td>
<td>Patients with ID</td>
<td>Controls</td>
</tr>
<tr>
<td>Frequent consulters (≥9.1) per yearb</td>
<td>260</td>
<td>136</td>
<td>2.71 (1.91 to 3.84)</td>
<td>277</td>
</tr>
<tr>
<td>Frequent CVD medication prescriptions (≥1.8) per yeara</td>
<td>130 (50.0)</td>
<td>30.3 (28.2)</td>
<td>0.91 (0.62 to 1.32)</td>
<td>111 (40.1)</td>
</tr>
<tr>
<td>LDL measurement (only those aged &lt;80 years) in 2018</td>
<td>69 (26.5)</td>
<td>304 (26.9)</td>
<td>1.02 (0.73 to 1.43)</td>
<td>88 (31.8)</td>
</tr>
<tr>
<td>Blood pressure test in 2018</td>
<td>205 (78.8)</td>
<td>1027 (78.0)</td>
<td>0.96 (0.65 to 1.42)</td>
<td>81 (29.2)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>Patients with ID</td>
<td>Controls</td>
<td>Patients with ID</td>
<td>Controls</td>
</tr>
<tr>
<td>Frequent consulters (≥8.3) per yearb</td>
<td>1105</td>
<td>4739</td>
<td>2.49 (2.14 to 2.89)</td>
<td>402</td>
</tr>
<tr>
<td>Frequent diabetes mellitus medication prescriptions (≥1.8) per yeara</td>
<td>607 (54.9)</td>
<td>1582 (33.4)</td>
<td>1.57 (0.91 to 1.25)</td>
<td>159 (39.6)</td>
</tr>
<tr>
<td>Albuminuria test in 2018</td>
<td>1000 (90.5)</td>
<td>4205 (88.6)</td>
<td>1.20 (0.94 to 1.53)</td>
<td>148 (36.8)</td>
</tr>
<tr>
<td>COPD</td>
<td>Patients with ID</td>
<td>Controls</td>
<td>Patients with ID</td>
<td>Controls</td>
</tr>
<tr>
<td>Frequent consulters (≥9.3) per yearb</td>
<td>302</td>
<td>2137</td>
<td>3.01 (2.18 to 4.16)</td>
<td>393</td>
</tr>
<tr>
<td>Frequent COPD medication prescriptions (≥1.8) per yeara</td>
<td>174 (57.6)</td>
<td>490 (34.1)</td>
<td>1.07 (0.78 to 1.46)</td>
<td>137 (34.9)</td>
</tr>
<tr>
<td>Smoking behaviour discussed in 2018</td>
<td>110/139 (79.1)</td>
<td>519/655 (79.2)</td>
<td>1.04 (0.78 to 1.39)</td>
<td>80/99 (80.8)</td>
</tr>
<tr>
<td>Albuminuria test in 2018</td>
<td>856 (77.5)</td>
<td>3747 (79.1)</td>
<td>0.88 (0.74 to 1.05)</td>
<td>115 (28.6)</td>
</tr>
<tr>
<td>Smoking behaviour discussed in 2018</td>
<td>243 (80.5)</td>
<td>1123 (78.1)</td>
<td>1.32 (0.89 to 1.95)</td>
<td>61 (15.5)</td>
</tr>
</tbody>
</table>

aThe 2018 DMP guidelines state that all monitoring tests should take place once a year. bWeighted average (by patients’ registration time in general practice) of number of contacts between patients and GPs (for example, regular consultations and home visits) between 2015 and 2018. For CVD, this average was 9.1 consultations per year, for diabetes mellitus 8.3 per year, and for COPD 9.3 per year. cWeighted average (by patients’ registration time in general practice) of medication prescriptions between 2015 and 2018 across the study populations. dWeighted average (by patients’ registration time in general practice) of number of contacts between patients and GPs (for example, regular consultations and home visits) between 2015 and 2018. eComparison with existing literature

Therefore it has been possible to make more robust claims about a larger group of patients with ID than is possible by using solely GP records.7,34

Thanks to the matched study groups, the authors limited influences of sociodemographic factors and acknowledged the different demography of the ID population.7 As previous research has shown that these factors are important in the prevalence of chronic diseases and care utilisation in people with ID, as well as enrolment in DMPs, the risk of wrongly assigning patients was reduced and this provided a more precise image than by focusing solely on one method. Use of NPCD, containing information directly derived from clinical practice, allowed the examination of enrolment and disease monitoring as objectively as possible. However, the current findings do not fully comply with the 2018 benchmark from the national primary care organisation InEen. Unlike NPCD, this benchmark contains solely information from general practices, which are part of regional care groups.40 Future research should therefore consider regional differences.

Besides insufficient registration for DMP enrolment, registration for routine examinations and medication prescriptions is also most likely incomplete. Perhaps care providers registered routine examinations and medication prescriptions more thoroughly for those enrolled in DMPs because of DMP-related financial incentives.4 Although 85% of the total study population had no medication prescriptions, missing data occurred at a similar frequency for people with and without ID.

To the best of the authors’ knowledge, DMP enrolment for patients with and without ID has not yet been studied, making comparison difficult. The current finding that patients with ID are often enrolled in diabetes mellitus-DMP could reflect...
their increased disease burden, as DMP enrolment is often higher among those with a higher disease burden and of younger ages.\textsuperscript{33,35,41} However, future research could examine the influence of socioeconomic determinants of enrolment in people with and without ID.

No studies, to the authors' knowledge, have been identified that have examined disease monitoring by DMP enrolment for patients with ID. Disregarding DMP enrolment, similar to previous studies, the current study found that patients with ID have higher consultation rates than those without ID, and in general have high medication use.\textsuperscript{8,34,42,43} Although medication in people with ID may be prescribed more often to regulate challenging behaviour,\textsuperscript{34,45} this study was unable to consider medication type in the analyses.

The current finding that the frequency of routine examinations did not differ between those with and without ID conflicts with previous research. Most studies showed fewer tests in people with ID compared with the general population. Often, patients with both ID and CVD were found to receive fewer cholesterol and blood pressure tests, those with diabetes mellitus received microalbuminuria or HbA1c tests less often, and those with COPD discussed their smoking status or had smoking cessation advice less often than their controls.\textsuperscript{19,20,22,24} Several reasons can be proposed for these seemingly contradictory findings.

First, perhaps this study's novel focus on investigating DMP enrolment before examining monitoring accounted for these differences: it could be that the financial incentives to stimulate DMP enrolment ensure increased compliance with chronic disease guidelines. Second, by innovatively linking administrative data to medical records, a more thorough identification of the people in the ID group was achieved. However, future research should further investigate these differences.

Among those not enrolled in DMPs, this study found that most tests for routine examinations were more often administered in patients with ID. Nevertheless, patients with (and without) ID not enrolled in DMPs still received fewer routine examinations than those enrolled. To the best of the authors' knowledge, no previous studies have examined similar research questions. Research on patients' experiences and outcomes is therefore required to interpret findings on routine examinations within and outside DMPs for patients with ID.

**Implications for practice**

This study is the first, to the authors' knowledge, to explore DMP enrolment and disease monitoring in the Netherlands for patients with chronic illness with and without ID. Although previous studies on disease monitoring among patients with ID often reveal a rather unfavourable image for these patients compared with the general population, this study shows that focusing on DMP enrolment can reveal other patterns: both patients with and without ID benefit hugely from DMP enrolment. As DMPs often improve clinical outcomes and quality of care for patients with chronic illness,\textsuperscript{33,46,47} policymakers should encourage healthcare insurers and care providers to provide suitable (financial) incentives for enrolling patients in DMPs.\textsuperscript{35} Patients with ID not enrolled in DMPs should be monitored regularly, as their already poorer health might further deteriorate without adequate recognition of health conditions.\textsuperscript{48} With their strong generalist skills, GPs have a solid foundation to address the complex healthcare needs of patients with ID.\textsuperscript{48} Despite the similarities in enrolment, awareness of patients' individual care needs is thus an essential starting point for equitable and suitable chronic disease management.\textsuperscript{15,49}

---

**Data availability**

The data underlying this article were provided by Nivel by permission. Data will be shared on request to the corresponding author with Nivel's permission.

**Provenance**

Freely submitted; externally peer reviewed.

**Competing interests**

The authors have declared no competing interests.

**Acknowledgements**

The authors would like to express their thanks to statisticians Petra Koopmans and Rogier Donders for their useful and valuable help with the statistical analyses.

**Open access**

This article is Open Access: CC BY 4.0 licence (http://creativecommons.org/licenses/by/4.0/).

**Discuss this article**: bjgp.org/letters
REFERENCES


