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Long-term restrictions in participation in stroke survivors under and over 70 years of age

Joris A. de Graaf, Maria L. van Mierlo, Marcel W. M. Post, Wilco P. Achterberg, L. Jaap Kappelle and Johanna M. A. Visser-Meily

ABSTRACT
Purpose: This study aims to (1) assess differences in participation restrictions between stroke survivors aged under and over 70 years and (2) identify predictors associated with favorable and unfavorable long-term participation in both age groups.

Methods: Prospective cohort study in which 326 patients were assessed at stroke onset, two months and one year after stroke. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) was used to measure participation restrictions one year after stroke. Bivariate and multivariate logistic regression analyses were performed including demographic factors, stroke-related factors, emotional functioning and comorbidity as possible predictors.

Results: Stroke survivors aged over 70 years perceived more participation restrictions in comparison to stroke survivors aged under 70 years one year after stroke. Independently significant predictors for unfavorable participation outcomes were advancing age, more severe stroke and anxiety symptoms in patients aged over 70 years, and female gender, more severe stroke, impaired cognition and depression symptoms in patients aged under 70 years. Lower age was the only independent predictor associated with favorable participation after one year in stroke survivors aged over 70 years.

Conclusions: This study emphasizes the need to pay more attention to participation restrictions in elderly stroke survivors.

Introduction
Stroke is one of the most common causes of disability. In the Netherlands, the annual incidence of stroke is between 34,000 and 41,000 patients, ranging from 0.7/1000 for people under 55 years old to 15/1000 for people over 70 years old [1]. Therefore, stroke is truly a disease of the elderly [2]. Major improvements in the acute treatment of stroke, such as thrombolysis and the implementation of stroke units, have increased post stroke survival rates [3]. Consequently, an increasing number of stroke survivors have to deal with long-term stroke sequelae, including psychosocial consequences and participation restrictions [4].

According to the International Classification of Functioning, Disability and Health (ICF), participation can be defined as “the person’s involvement in a life situation” [5], including daily activities as well as social roles [6]. Stroke survivors often experience participation restrictions in the chronic phase, despite being independent in basic activities of daily living [7].

After stroke onset, participation improves in the first three to six months, followed by a stable phase [8-11]. Several factors have been found to contribute to participation restrictions after stroke, including cognitive deficits [12,13], emotional deficits [14,15], psychological factors [16,17], functional dependency [18], comorbidities [19] and increasing age [14,19,20]. Because of the increasing number of old stroke survivors and the association between age and participation restrictions, more research is needed to gain insight into the prediction and improvement of participation in the elderly [21]. To the best of our knowledge,
predictors of long-term participation has never been determined for young and old stroke survivors separately.

Old and young stroke survivors have different participation needs, influenced by age-related changes in social status, retirement and co-morbid factors [22]. In stroke survivors at vocational age, an important rehabilitation goal is returning to work. Participation needs in the elderly are mostly not related to work but to all other domains of participation and seem to be more complex for this reason [23]. Moreover, age-related factors such as a higher incidence of comorbidity, less social support and impaired compensatory abilities make older stroke survivors particularly more likely to have difficulties in long-term participation [24,25]. Therefore, reintegration in the community after stroke remains a huge challenge for the elderly [23,26].

Hence, more attention should be paid to older stroke survivors who are at risk of adverse participation outcome. Short-term predictors of participation in older stroke survivors have been assessed in only one study. This study identified decreased walking abilities, severity of stroke, increasing age, depression symptoms and cognitive deficits as predictors of favorable participation outcome until six months after stroke in stroke survivors aged over 65 years [27]. A comparison of participation restrictions and its determinants between younger and older stroke patients has not been published to date. Therefore, this study aims to assess differences in participation restrictions between stroke survivors over 70 years and under 70 years old. The cutoff point of 70-year old was chosen since; on the one side, we aimed for a high cutoff because we expected the most distinct patterns of participation in the oldest patients, but on the other hand needed adequate sample sizes in both age groups. Besides, we hypothesized participation needs of patients over 70-year old change as the retirement age has just been passed. Furthermore, predictors associated with favorable and unfavorable long-term participation will be identified in both age groups.

Methods

Design

The present study is part of the multicenter prospective longitudinal Restore4Stroke Cohort study and used data collected at stroke onset, two months and one year after stroke [3]. Six general hospitals in the Netherlands participated. The medical ethical committees of all participating hospitals gave approval for this study. Written informed consent was obtained from all included patients.

The first assessment took place within the first week after stroke and concerned demographic and stroke-related factors. Demographical factors were obtained from the patient or from family members. Stroke-related factors were extracted from the medical charts as assessed by the neurologist on the fourth day after stroke. At two months after stroke, comorbidity and emotional and cognitive functioning were assessed. Patients were asked to complete self-report scales on emotional functioning. Screening on comorbidity and cognitive functioning was conducted by a trained research assistant. At one year after stroke, a follow-up assessment took place during which patients were asked to complete the self-report scale of participation.

Participants

Stroke patients were enrolled in the Restore4Stroke Cohort study between March 2011 and March 2013. Stroke patients were eligible if they had a clinically confirmed diagnosis of ischemic or hemorrhagic stroke within seven days after symptom onset, and were at least 18-year old. Patients were excluded from the study if they (1) had a serious other condition that could interfere with study outcome; (2) had been dependent in basic Activities of Daily Living (ADL) before the stroke occurred (defined by a Barthel Index (BI) score of ≤ 17 [28]); (3) had insufficient command of Dutch language, based on clinical judgment; or (4) had suffered cognitive decline prior to the stroke (defined by a score of ≥ 1 on the Heteroamnesis List Cognition [29]). Patients who completed the USER-Participation at one year after stroke were included in the analysis.

Dependent variables

In this study, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) restrictions subscale was used to measure participation [7]. The restrictions subscale consists of eleven items, concerning difficulties experienced with vocational, leisure and social activities caused by the stroke. For each item four response categories are available ("not possible," "with assistance," "with difficulty," and "without difficulty"). A "not applicable" option is available for all items in case a restriction is not attributed to the stroke. The total score of the restrictions subscale ranges from 0–100, and is based on items that are applicable. A higher score indicates a higher level of participation (fewer experienced restrictions). The USER-Participation has previously shown satisfactory validity and reliability in stroke patients [30].

Independent variables

Demographic factors

Information about gender, age, marital status and level of education was collected. The Dutch classification system of Verhage [31] was used to assess level of education. Scores range from 1–7 and were dichotomized into low (up to completed secondary education, 1–5) and high (completed university, secondary professional education or higher, 6–7).

Stroke-related factors

Information about severity of stroke, history of stroke, hemisphere, stroke type, ADL dependency, cognitive functioning, length of stay in the hospital and discharge destination was collected. Stroke severity was assessed with the National Institutes of Health Stroke Scale (NIHSS) four days after stroke [32]. Scores range from 0–42 and increasing scores indicate more severe strokes. ADL dependency was assessed using the BI four days after stroke. Scores range from 0–20 and were dichotomized into “ADL dependent” (BI ≤ 17) and “ADL independent” (BI > 17) [33]. BI is a validated measure often used in stroke [28]. Cognitive functioning two months after stroke was assessed using the Montreal Cognitive Assessment (MoCA). Scores range from 0–30 and were dichotomized into “cognitive problems” (MoCA ≤ 25) and “no cognitive problems” (MoCA > 25). The MoCA is a brief cognitive screening tool which is also validated for stroke patients [34]. Discharge destination after hospitalization was categorized into home or inpatient rehabilitation. Inpatient rehabilitation includes geriatric rehabilitation in a nursing home (low-intensity rehabilitation) and rehabilitation in a rehabilitation center (high-intensity rehabilitation).

Emotional functioning

The Hospital Anxiety and Depression Scale (HADS) was used to assess the presence of symptoms of depression or anxiety two months after stroke. This scale consists of 14 items, which are
subdivided into seven items about anxiety (HADS-A) and seven items about depression symptoms (HADS-D). Separate scores for the presence of depression symptoms and the presence of anxiety symptoms were calculated. Each item is scored on a four point scale (0–3) and a higher score indicates more emotional problems. The HADS-A scores range from 0–21 and were dichotomized into “absence of symptoms of anxiety” (HADS-A < 8) and “presence of symptoms of anxiety” (HADS-A ≥ 8). The HADS-D scores range from 0–21 and were dichotomized into “absence of symptoms of depression” (HADS-D < 8) and “presence of symptoms of depression” (HADS-D ≥ 8) [35]. The HADS is often used in stroke patients and has shown good psychometric properties [36].

Comorbidity
Comorbidity was assessed with the Cumulative Illness Rating Scale (CIRS) two months after stroke [37]. This scale measures physical impairment with 13 items based on 13 organ areas. Item 11 (neurological impairment) is not included in the analysis, since stroke itself is incorporated in this item.

Statistical analysis
All analyses were conducted with IBM SPSS statistics version 23 (IBM Corp., Armonk, NY). Descriptive statistics were used to describe patients’ characteristics and dependent variables.

USER-participation item score one year after stroke
The USER-Participation restrictions items were dichotomized to quantify the presence of persisting restrictions. “With difficulty,” “with assistance,” and “not possible” were defined as “restrictions” and “without difficulty” was defined as “no restrictions”. Chi-square statistics were calculated on the restriction items to ascertain the differences in participation restrictions between stroke survivors aged over 70 years and under 70 years.

Logistic regression analyses
To determine predictors of favorable and unfavorable participation in patients aged over 70 years and under 70 years one year after stroke, logistic regression analyses were performed. To determine favorable and unfavorable participation outcomes, the USER-Participation restrictions scores were dichotomized into high participation level (best quartile) versus the rest and low participation level (worst quartile) versus the rest, respectively. The USER-P restrictions scores in the best quartile were all 100 (maximum score) in both patients over and under 70-year old. The USER-P Restrictions scores in the worst quartile ranged from 16.7–55.6 in patients over 70-year old and from 14.3–70.0 in patients under 70-year old. Bivariate logistic regression analyses were used to identify bivariately significant determinants of favorable and unfavorable participation scores in patients over and under 70 years of age. Demographic factors, stroke-related factors, emotional functioning two months after stroke and comorbidity were entered as covariates in all bivariate analyses. Bivariately significant variables (p < 0.10) were included into the multivariate analyses. Possible multicollinearity was checked (VIF < 4), which did not reveal any problems. The Hosmer–Lemeshow test was used to assess the goodness of fit of the multivariate model. Odds ratios and their 95% confidence intervals were calculated. A p < 0.05 was considered as statistical significant.

Results
A total of 395 patients were included in the Restore4Stroke Cohort study. At one year after stroke, datasets of 326 patients were available for analyses. A total of 69 patients (17.5%) dropped out during the study: eight patients (2.0%) had died, 32 patients (8.1%) refused further participation and 29 patients (7.3%) were lost to follow-up. There were no significant differences in terms of baseline characteristics between patients and drop-outs.

Patient characteristics are presented in Table 1. Patients who were over 70-year old at stroke onset were significantly more likely to live alone, be more ADL dependent, more cognitively impaired, have more comorbidities and less likely to be discharged home compared to patients who were under 70-year old at stroke onset. Patients under 70-year old had significantly more anxiety symptoms at baseline compared to patients over 70-year old, whereas depression symptoms were equally present in both age groups.

Restrictions in participation one year after stroke
After one year, many stroke survivors still experienced restrictions in items regarding mobility, such as housekeeping (53.7%), physical exercise (55.9%) and outdoor activities (51.6%). Relatively less stroke survivors experienced restrictions in social items, such as visits from family/friends (22.0%), telephone/PC contact (20.3%), partner relationship (35.1%) and leisure indoors (29.8%).

At one year after stroke, the mean USER-Participation Restrictions score was significantly worse in patients over 70-year old and they experienced significantly more restrictions on the items housekeeping (p = 0.036), outdoor mobility (p < 0.001), going out (p = 0.023), outdoor activities (p = 0.019) and visits to family or friends (p < 0.001) compared to patients under 70-year old.

Patients over 70-year old
Bivariate analyses
The bivariate analyses showed that advancing age, an increased severity of stroke, the presence of anxiety symptoms and more comorbidity were associated with unfavorable participation outcomes (Table 2). Favorable participation outcomes were associated with lower age, ADL independency, a decreased severity of stroke, the absence of depression or anxiety symptoms and less comorbidity.

Multivariate analyses
The multivariate logistic regression analyses showed that advancing age, an increased severity of stroke and the presence of anxiety symptoms were independently associated with unfavorable participation outcomes in patients over 70-year old (Table 2). A reasonable fit of the multivariate model was found (Hosmer–Lemeshow test, p = 0.644), although the amount of explained variance was low (Nagelkerke R² = 0.165). Favorable participation outcomes were independently associated with a lower age. This multivariate model also showed a reasonable fit (Hosmer–Lemeshow test, p = 0.283) and the amount of explained variance was somewhat higher (Nagelkerke R² = 0.255).

Patients under 70-year old
Bivariate analyses
The bivariate analyses showed that female gender, an increase in severity of stroke, ADL dependency, impaired cognitive functioning and the presence of depression symptoms were associated
with unfavorable participation outcomes (Table 3). Favorable participation outcomes were associated with male gender, ADL independence, the absence of depression and anxiety symptoms and less comorbidity.

Multivariate analyses
The multivariate logistic regression analyses showed that female gender, an increase in severity of stroke, impaired cognitive functioning, and the presence of depression symptoms were independently associated with unfavorable participation outcomes in patients under 70-year old (Table 3). A reasonable fit of the multivariate model was found (Hosmer–Lemeshow test, $p = 0.337$), although the amount of explained variance was low (Nagelkerke $R^2 = 0.228$). None of the variables were independently associated with favorable participation outcomes. This multivariate model also showed a reasonable fit (Hosmer–Lemeshow test, $p = 0.628$), although the amount of explained variance was low (Nagelkerke $R^2 = 0.187$).

Discussion
This study shows that stroke survivors from general hospitals experience considerable restrictions after one year, regardless of discharge destination. Especially activities involving mobility, such as physical exercise and outdoor activities, were severely restricted after one year. This particularly applies to stroke survivors aged over 70 years, since they were significantly more restricted in these items compared to stroke survivors aged under 70 years. Previous literature concluded that up to 50% of stroke survivors after rehabilitation perceived participation problems in physical exercise, regardless of age [7].

Predictors of unfavorable participation outcome
In both age groups, survivors of a more severe stroke perceived more long-term participation restrictions. This finding has previously been observed [14,18,19] and suggests that further
Table 2. Bivariate and multivariate analyses: predictors for unfavorable (worst quartile) and favorable (best quartile) USER-participation scores one year after stroke in patients ≥70 years old.

<table>
<thead>
<tr>
<th>Factors (measure)</th>
<th>Reference</th>
<th>Bivariate analysis</th>
<th>Multivariate analysis</th>
<th>Reference</th>
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ADL: activities of daily living; BI: Barthel Index; CI: confidence interval; CIRS: Cumulative Illness Rating Scale; HADS-A: Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale-Depression subscale; MoCA: Montreal Cognitive Assessment; MoCA: Montreal Cognitive Assessment; NIHSS: National Institutes of Health Stroke Scale; OR: odds ratio; SE: standard error; β: standardized regression coefficient.

*p values are significant (p < 0.05).
Table 3. Bivariate and multivariate analyzes: predictors for unfavorable (worst quartile) and favorable (best quartile) USER-participation scores one year after stroke in patients <70 years old.

<table>
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<tr>
<th>Factors (measure)</th>
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<th>β</th>
<th>SE</th>
<th>p values</th>
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<tr>
<td>Cognitive functioning</td>
<td>MoCA &gt; 25</td>
<td>174</td>
<td>0.64</td>
<td>0.38</td>
<td>0.090</td>
<td>1.89 (0.91–3.95)</td>
<td>0.88</td>
<td>0.44</td>
<td>0.047</td>
<td>2.41 (1.01–5.76)</td>
<td>174</td>
<td>−0.49</td>
<td>0.32</td>
<td>0.126</td>
</tr>
<tr>
<td><strong>Emotional functioning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression symptoms</td>
<td>HADS-D &lt;8</td>
<td>171</td>
<td>1.41</td>
<td>0.4</td>
<td>0.003</td>
<td>4.08 (1.86–9.87)</td>
<td>1.43</td>
<td>0.44</td>
<td>0.001</td>
<td>4.17 (1.77–9.83)</td>
<td>171</td>
<td>1.57</td>
<td>0.51</td>
<td>0.002</td>
</tr>
<tr>
<td>Anxiety symptoms</td>
<td>HADS-A &lt;8</td>
<td>171</td>
<td>0.53</td>
<td>0.4</td>
<td>0.183</td>
<td>1.70 (0.78–3.71)</td>
<td>171</td>
<td>0.15</td>
<td>0.47</td>
<td>0.220</td>
<td>0.89</td>
<td>0.54</td>
<td>0.103</td>
<td>0.41 (0.14–1.19)</td>
</tr>
<tr>
<td>Comorbidity (CIRS)</td>
<td></td>
<td>178</td>
<td>0.08</td>
<td>0.07</td>
<td>0.215</td>
<td>1.09 (0.95–1.24)</td>
<td>0.18</td>
<td>0.64</td>
<td>0.064</td>
<td>0.88 (0.77–1.01)</td>
<td>178</td>
<td>0.13</td>
<td>0.07</td>
<td>0.684</td>
</tr>
</tbody>
</table>

ADL: activities of daily living; BI: Barthel Index; CI: confidence interval; CIRS: Cumulative Illness Rating Scale; HADS-A: Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D: Hospital Anxiety and Depression Scale-Depression subscale; MoCA: Montreal Cognitive Assessment; NIHSS: National Institutes of Health Stroke Scale; OR: odds ratio; SE: standard error; β: standardized regression coefficient.

*p values are significant (p < 0.05).
developments in the treatment of (sub)acute stroke may be expected to lead to improvements in long-term participation restrictions.

Emotional functioning also plays an important role in the prediction of long-term participation restrictions, as anxiety symptoms in patients aged over 70 years and depression symptoms in patient aged under 70 years are independently associated with unfavorable participation outcomes. This is the first study highlighting the importance of anxiety symptoms as predictor of unfavorable long-term participation after stroke. As anxiety after stroke occurs frequently and can be treated with psychoeducation, cognitive therapy, antidepressants or other anxiety-reducing drugs [38], detecting symptoms of anxiety in stroke survivor aged over 70 years could potentially improve long-term participation.

The negative influence of depression symptoms has been found in previous studies as well and can be prevented by adequate and timely treatment too [14,15,27]. These results point out the importance of early screening and treatment of deficits in emotional functioning after stroke, in which attention should be paid to the presence of both depression as anxiety symptoms.

Also, this study shows impaired cognitive function after stroke is a predictor of unfavorable long-term participation in stroke survivors aged under 70 years. Contradictory results have been reported about the influence of cognitive function and participation in current literature. Two studies found a negative association between impaired cognitive function and participation in stroke survivors after six months [13,27], whereas one of these studies also observed improvement of long-term participation despite the presence of impaired cognitive function [39]. Moreover, not all domains of participation are influenced by the presence of cognitive deficits in stroke survivors aged over 65 years old [39]. This study adds to existing literature that the association between cognitive deficits and long-term participation may be age-dependent.

Advancing age in stroke survivors aged over 70 years is associated with restrictions in participation after one year. The attribution of the normal aging process should be taken into account, as an increase in perceived restrictions has also been observed in healthy adults after the age of 80 years [40]. However, using the USER-Participation restrictions subscale, patients were asked for restrictions in participation specifically caused by the stroke. The association between age and long-term participation restrictions might be partly explained by the increasing burden of comorbidities at advancing age, since age and comorbidity are closely related. This might also explain the lack of an association between comorbidity and long-term participation restrictions in the multivariate analyses. Although current literature is inconsistent about the association between comorbidity and functional outcome in older stroke survivors [24,41,42], one study identified comorbidity as independent predictor of long-term participation [19].

Lastly, female gender is only negatively associated with long-term participation in stroke survivors aged under 70 years. This might be due to different activities of women at vocational age compared to men. This is a new finding in literature, suggesting female stroke survivors aged under 70 years should be watched closely.

Predictors of favorable participation outcome

Lower age is the only independent predictor associated with favorable participation after one year in stroke survivors aged over 70 years, whereas no independent positive predictors in stroke survivors aged under 70 years have been found. The positive association between lower age and participation confirms the importance of age in the prediction of long-term participation restrictions. Furthermore, despite the importance of having a spouse for determining discharge destination was highlighted by a recent study [43], the presence or absence of a spouse was not associated with favorable or unfavorable participation one year after stroke.

Although predictors of favorable participation are scarce in this study, it is noteworthy that predictors of favorable participation are not just the opposite of predictors of unfavorable participation. For this reason, future research should keep differentiating between predictors of favorable and unfavorable participation.

Remarkably, only 17–26% of the variance could be explained in current prediction models. One explanation is the potential influence of additional factors such as environmental and psychological factors on participation. Therefore, these factors need further research to gain better insight into predictors positively and negatively influencing long-term participation which are potentially modifiable by interventions. Positive affect [44], self-esteem [45] and hopeful thinking [16] have been found to positively influence participation.

Study strengths

The large number of participants was one of the main strengths of this longitudinal multicenter study. Also, patients were recruited in six general hospitals, well-representing the general stroke population. Furthermore, all patients were included within seven days after stroke and a wide variety of clinical and demographic factors were obtained and included in the analyses. Moreover, despite the association between age and participation is known, this study is, to the best of our knowledge, the first to compare long-term restrictions in participation between old and young stroke survivors. Besides, predictors of favorable participation have never been assessed in current literature as far as we know. Lastly, differences between both age groups were studied per participation item, providing detailed insights into participation restrictions.

Study limitations

Firstly, the large number of participants consisted mainly of patients with relatively mild strokes, possibly due to the exclusion of patients with premorbid cognitive deficits or ADL dependency. Besides patients with a severe stroke may not be able to give their informed consent in the first week after stroke. Therefore, the most vulnerable patients were probably less represented in our study population which may decrease the generalizability of the results. Secondly, although the USER-Participation is a validated tool to measure participation post stroke, this questionnaire has never been validated for the elderly. Common activities for the elderly are perhaps less represented in the questionnaire. Thirdly, this study did not take environmental and personal factors into account, while these factors could possibly have influenced long-term participation.

Clinical message

The findings of the current study emphasize the need to pay more attention to stroke survivors aged over 70 years, since more restrictions in participation were perceived in comparison to younger stroke survivors one year after stroke. Therefore, general practitioners should consider to incorporate participation in the follow-up assessment of stroke survivors to detect potential restrictions in participations as early as possible. Furthermore, different predictors for long-term participation restrictions after stroke were found for stroke survivors aged over and under
70 years, suggesting a different approach to older stroke survivors regarding maintaining long-term participation after stroke is needed compared to young stroke survivors. In this context, this study highlights the importance of early recognition of anxiety symptoms in patients aged over 70 years and depression symptoms in patients aged under 70 years to prevent long-term restrictions in participation.

Early screening on deficits in emotional functioning in stroke survivors can easily be achieved by using a brief screener such as the HADS. In contrast to other depression scales, the HADS measures both the presence of anxiety and depressive symptoms. This could potentially prevent long-term restrictions in participation in stroke survivors aged over 70 years old, since the presence of anxiety symptoms rather than the depression symptoms causes restrictions in long-term participation in this age group.

Lastly, a need for community based follow-up programs to promote physical activity has been observed in the current study, as restrictions with mobility and outdoor activities one year after stroke were considerable. Promoting and monitoring physical activity in the community gives not only the possibility to add years to a stroke survivor’s life, but also adds quality of life to their years.

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Disclosure statement

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