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Donor education campaigns since the introduction of the Dutch organ donation act: increased cohesion between campaigns has paid off

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SUMMARY

Governments utilize special policy measures to increase and maintain positive attitudes among their citizens towards consent registration and organ donation. Little has been published on these national strategies. Some studies report on the impact of single policy measures shortly after their implementation, whereas the assessment of the impact of a national strategy on organ donation over a long period of time has been lacking. The aim of this study is to assess the impact of the Dutch donor education strategy (1998–2008) on the availability of donor organs, by trying to disentangle the impact of education from other factors. In this study, we have devised a research strategy to assess the impact of policy measures at national level, while providing information about Dutch initiatives to increase registration and procurement rates, and demonstrating and explaining these increases. The increased resources and improved strategies employed to educate the public in relation to organ donation have paid off, but the impact decreases over time. The question remains whether the effects of these policy measures will further level off over time and what levels of increase in donor registration rates and efficiency of donor procurement are realistic targets to achieve.

INTRODUCTION

All western-European countries are faced with a large shortage of donor organs [1–6]. As donor organs are scarce and patients are dying while waiting for an organ, the loss of potential donors (deceased people who are medically suitable) should be reduced to a minimum.

An important issue which causes a loss of potential donors is obtaining consent for organ donation [7–9]. To support the procedure of obtaining consent, countries employ either presumed or explicit consent systems. Regardless of the consent system, it has been established that in each country next of kin play an important role in the removal of a deceased's organs [10–13]. Therefore, governments implement policy measures in the field of public education to encourage citizens to take a stand on organ donation and they develop strategies to increase and maintain positive attitudes towards organ donation.

Similar to the UK, in the Netherlands there is an ongoing debate on the organ shortage [14,15]. In the UK, the Organ Donation Taskforce embarked in 2006 on a process of identifying obstacles to organ donation. The Taskforce identified the lack of a structured and systematic approach to organ donation in the past and emphasized the importance of additional policy measures [16]; these findings are in line with other studies [17–19]. One of the recommendations of the Taskforce includes the identification and implementation of the most effective methods through which organ donation can be promoted to the general public.

In the Netherlands in 1998, the Dutch Organ Donation Act was introduced, heralding increased government effort regarding policy measures to support organ donation. An important aim of the Dutch strategy is to increase and maintain positive attitudes among citizens towards organ donation. This strategy has been implemented by the Dutch Ministry of Health, the Dutch Donor Register and NIGZ Donor Education. Additionally, charities, such as the Dutch Kidney Foundation and the Dutch Heart Foundation, support this strategy. One of the key aims of such charity organizations is to improve patient care.

Almost 10 years after the introduction of the Organ Donation Act questions were raised as to the impact of this strategy on increasing and maintaining positive attitudes among citizens towards organ donation.

In spite of the importance of effective policy measures, little has been published on these measures and their impact. It is difficult to gain insight into the strategies of governments and the additional policy measures implemented by governments over a period of several years [17].

Additionally, assessing the impact of national strategies for organ donation is a difficult issue. The evaluation of national strategies for organ donation cannot be the subject of an experimental research approach, as many factors influence the availability of donor organs and the effects of campaigns are rather indirect and difficult to quantify. For example, while an education campaign may not lead directly to more donors; it might influence the attitude of citizens and might in turn induce them to register their consent. In the Netherlands, consent rates for potential donors that registered consent are much higher than consent rates for unregistered potential donors (92% vs. 30% [20]).

The aim of this study was to assess the impact of the Dutch donor education strategy on the availability of donor organs, by trying to disentangle the impact of education from other factors. Additionally, we sought to provide feedback on the impact of the Dutch donor education strategy together with proposing a strategy for analysing the impact of such policy measures over time.

METHOD

Assessing the policy strategy

To gain insight into the donor education strategy we assessed the contents of the national policy on donor education (1998–2007). The overview of policy measures carried out in this period was obtained by analysing policy documents of the Ministry of Health and the annual reports of both the Donor Register, and NIGZ Donor Education.

Assessing direct effects and indirect effects

When studying the effects of donor education, we distinguished between direct and indirect effects. Direct effects are directly attributable to individual policy measures, such as the range of a campaign and its effects on attitudes and/or registration. To establish the direct effects we studied the specific evaluation reports of these policy measures.

The indirect effects of the successive donor education campaigns are reflected by the development of the annual rates of the Donor Register (secondary effects) and the development of donor procurement itself (final effects). The developments in registration and procurement give insight into the overall impact of the Dutch policy.

Assessing donor procurement

National organ donation rates depend largely on a country's mortality rates for cerebral vascular accidents (CVA) and (traffic) accidents (<65 years). Relevant mortality rates are a good proxy for donor potential [17,21–23]; exact data on ICU death which is relevant for organ donation are not available in the Netherlands. These mortality rates differ over time, which contributes to differences in donation rates between periods, and may obscure one's understanding of the impact of donor education strategy throughout the years. Therefore, we have adjusted the organ donation rates for differences in relevant mortality rates between years. In this study we call this adjustment 'the donor efficiency rates by proxy'.

The donor efficiency rates by proxy were calculated by using the following definition: [National donation rates (PMI)/relevant national mortality rates (PMI)]*100 [21].

THE DUTCH STRATEGY ON DONOR EDUCATION

The Dutch strategy to increase and maintain positive attitudes towards organ donation among the public consists of policy measures in the field of public education, within the framework of a legal consent system.

The Dutch legal system of consent registration

A key element of the Dutch Organ Donation Act is the consent system, which is based on explicit consent registration and is implemented in the Donor Register. This Register contains roughly three options: (i) consent to organ removal or to removal of specific organs, (ii) objection to organ removal or (iii) leave the decision to next of kin or to a specific person [11]. The aim of the Donor Register is to provide clear information on the individual's wishes to those involved in the donation process (next of kin, medical staff). When a deceased is a suitable organ donor, but consent is not registered, his/her next of kin are asked for consent. Therefore the Dutch consent system is characterized as an explicit consent system. At the time, the government assumed that the introduction of the Act and the introduction of a new consent system, combined with public education, would increase the number of transplantable organs.

Additional policy measures in the field of public education

Donor education in the Netherlands is an ongoing activity. However, since the introduction of the Organ Donation Act (1998) there have been three important periods.

First period: Introduction of the Organ Donation Act in 1998

When the Organ Donation Act came into force, over 12 million registration forms were sent to all citizens of 18 years and older. This mailing was accompanied by a two tier public information campaign. This two tier approach was based on a study by Cleiren and Zoelen [24]. The first tier was an information campaign (Table 1) conducted on behalf of the government. In this campaign, the government did not take a stand on organ donation, but simply informed people about the possibility of registering an individual's wishes in the donor register. The aim of this campaign was to obtain as many registrations as possible. As a pilot study showed that a large part of the respondents (76%) said that it would return a registration form and would register in the National Register, the government expected a registration rate of 35–50% to be feasible.

[TABLE 1]

The aim of the second tier (Table 1) was to obtain as many registrations as possible, with the emphasis on registered consents. This tier was supported by several stakeholders (patients, The Dutch Transplantation Foundation and charities such as the Kidney Foundation and the Heart Foundation); it was more focused on convincing people to register their consent than the first tier. Both tiers of the campaign were carried out at the same time.

Additionally, the Foundation for Donor Information (later merged with NIGZ Donor Education) was funded to provide a call centre, respond to mail/email questions and provide extensive information material, including material for migrants, organize lectures and an exhibition and host a website.

To add to these initiatives, since 1998, the government has organized an annual campaign aimed at 18-year-olds sending them registration forms with the request to register their wish and return the form to the Donor Register [25,26].

Direct effects of the introduction of the Act

Zijdenbosch and Kamphuis [27] report in 1998 that, regarding the tools of the two tier campaign, 67% of their respondents ($n = 828$) remembered receiving the mail pack, 61% remember seeing the TV commercial, and 34% remembered seeing an advertisement in a newspaper.

At the end of 1998, 36% of adult citizens (almost 4.5 million people) had returned their registration form to the Donor Register [28]. Of these 4.5 million people 55% registered their consent for organ donation, 35% recorded their refusal and 10% registered that next of kin or a specified person should decide. The

overall registration rates correspond to the response rate of the annual campaigns targeting 18-years-olds, which have varied from 33% (2000) to 40% (2005).

Second period: The organ donation plan of action in 2000

One year after the Organ Donation Act came into force, donation rates dropped dramatically. In response, the Government (2000) announced additional policy measures to support organ donation. These policy measures included the 'organ donation plan of action', which marked a strategy change focussing more on specific initiatives. The plan contained measures (i) to support public education regarding organ donation, (ii) to increase the efficiency of the procurement of organs in hospitals and (iii) to find new pools of organ donors.

As a part of the 'organ donation plan of action' the government decided that the public campaigns (radio and TV commercials, newspaper advertisements and the activities aimed at 18-years-olds) should focus more on convincing people to register consent, rather than on registration in general (=consent and refusal). It was decided that the intensity of mass media interventions for organ donation should also be stepped up, and a multi-channel strategy was proposed.

To inform religious groups about the opinions of their religion on organ donation, NIGZ Donor Education has engaged with key persons from these groups since the implementation of the plan of action. Although no religion formally forbids organ donation, and only some orthodox Jews may have religious objections to opting in [29], it seemed that the attitudes of the members of some religious groups (both Christians as well as Muslims) were not conducive to organ donation. In 2006 a final statement was drafted by key persons of the Muslim community with the message that Islam is not considered to be a barrier for a Muslim to donate organs [30]. For churches as well as mosques information packages are available to inform their communities on the religious perspectives on organ donation.

Furthermore, several interventions, which were believed to increase registration rates and to have an impact on organ donation, were studied on their possible effects when implemented on a national level. These included a study on the cost effectiveness of a mail shot to all nonregistered residents [31], a pilot study on the effectiveness of handing out or mailing registration forms to those applying for a passport, identity card or driver's licence [32], and an analysis of reasons for nonregistration among nonregistered residents [33]. The outcomes of these pilot studies suggested that national implementation of these interventions would increase the number of registrations, and they were subsequently implemented during the next period.

Direct effects of the plan of action in 2000

In the second period no direct effects were reported. The measures proposed in the plan of action were piloted during the second period, but were implemented and evaluated during the third period.

Third period: The capitalization of donor education on an extensive public debate in 2004–2007

In early 2004 an extensive public debate on organ donation took place in the media. This debate was initiated by NIGZ when it proposed an alternative consent system combining the advantages of both explicit consent and presumed consent. Until then, the country had been divided into proponents of either the existing explicit consent system, or changing to a presumed consent system. The alternative system would be based on the existing explicit consent system, but if after several personal reminders to register, people still did not register either consent or refusal, they would be automatically registered as a donor. Hence, the alternative system combines what the NIGZ sees as the best of both systems; explicit consent registration and a large donor pool.

Many stakeholders (e.g. The Kidney Foundation, the Heart Foundation, the Transplant Foundation) supported the proposed alternative system and undertook strenuous efforts to promote this new system by using the media and by lobbying. The public debate on changing the consent system reached a crescendo in early 2005 when it seemed that the alternative consent system would be adopted by parliament. Despite these efforts the proposal was eventually rejected.

After the rejection of the alternative consent system, a sustained, comprehensive multi-channel campaign to promote donor registration and organ donation was initiated in 2005 by the government. This campaign capitalized on the existing public debate. The Kidney Foundation continued a campaign entitled ‘Are you informed?’. The aim of this campaign was to get people to talk to their next of kin and inform each other about their wish to become a donor or not. Meanwhile, in an initiative which originated from the plan of action, the government (supported by the Kidney Foundation and the Heart Foundation) sent out a mail shot to six million households. In addition, the Dutch commercial television network SBS6 broadcast a big charity show. The aim of these activities was to increase the number of registrations and to inform people about the shortage of donor organs.

Further to these initiatives, in spring 2007 two major events took place. Firstly, the NIGZ sent out registration forms to individuals in the age group that were thought to be most likely to register as a donor (45–49 years). In the second half of 2007 this campaign was repeated for the 50–54 years age group.

Secondly, in addition to the campaign initiated by the government, on 1 June 2007 the independent television network BNN, founded by a kidney patient, broadcast the controversial Big Donor Show. During the show several patients waiting for a kidney presented themselves and were interviewed. At the end of the show a supposedly ‘terminal patient’ chose one of these patients to donate a kidney to. This show received a lot of national and international media attention. The intensive debate generated by the broadcast highlighted the shortage of donor organs once again. It has to be noted that this event was an initiative by a private party and was not supported as such by the Dutch government.

Direct effects of the multi-channel campaign

The direct effects of the activities performed in 2005 (the campaign by the Kidney Foundation, the mail shots to six million households and the big TV charity show by SBS6 with 300 000 viewers) were evaluated by Cox [34], using a sample of 672 nonregistered citizens. The results of this study indicated that nearly all respondents (94%) remembered one or more of the campaigns. More than half of the respondents (57%) said that as a result of the campaigns they talked to their next of kin about organ donation.

For the first mail shot to the 45–49 years age group in spring 2007, 733 008 registration forms were sent out and 83 930 registration forms returned (response rate 11.5%), of which 47% were consent registrations for organ donation. The controversial Big Donor Show was broadcast in that same period and had 1.2 million viewers. Around the 15 July 2007 (1 month after the show), 12 000 new registrations, mostly consent registrations, were received by the Donor Register.

The second mail shot to the 50–54 years age group took place later that year. For this second batch 663 232 forms were sent out and 86 111 returned (response rate 13%), of which 40% were consent registrations [35].

In 2008 23 900 registration forms were returned by people who received their form when they applied for a passport, identity card or driver’s licence (65% consents, 25% refusals) and 13 774 were new registrations.

IDENTIFYING THE OVERALL EFFECTS OF THE DUTCH STRATEGY

Secondary effects (indirect): impact on registration rates

[FIGURE 1]

Figure 1 shows an increase in registrations from the introduction of the Organ Donation Act in 1998 until 2001. In 2002 the number of registrations declined. In 2005, the year marked by the Kidney Foundation campaign, the mail shots to six million household and the big TV charity show by SBS6, the number of registrations increased by 286 079 (6%). Seventy-seven percent of this increase consisted of registered consents [30]. Since that year we see a steady rise in the number of registrations. For the most part this increase is due to a larger number of registered consents. In 2007, when the age-group mailings and the Big Donor Show took place, the number of registrations in the Donor Register increased by 142 082 (2.8%). Seventy-two percent of this increase was attributable to a rise in the number of registered consents [30]. By the end of 2008, 5.3 million people had registered, of which three million consents and 1.6 million refusals (Figure 1).

Final effects (indirect): impact donor procurement

Figure 2 shows that shortly after the Organ Donation Act came into effect, donor procurement (shown by the donor efficiency rate by proxy) dropped considerably. After 2000, the procurement of donors showed an increase. This increase seemed to level off in 2005. In 2007, we see a further rise in donor procurement. However, taking into account the rate in 2008, this increase appears to be an incidental fluctuation.

[FIGURE 2]

There is a strong correlation between donor efficiency rates and total registration rates [Pearson correlation = 0.74 ($P < 0.01$)], and consent registration rates [Pearson correlation = 0.80 ($P < 0.01$)].

DISCUSSION

From separate interventions to cohesive multi-channel campaigns

At the time of the enactment of the Organ Donation Act, donor education in the Netherlands consisted of a number of separate measures with little cohesion between them. As a result of persisting low donor rates following the implementation of the Act, the government reshaped its strategy for donor education into a more cohesive multi-channel approach, focussing more on convincing people to register consent. The positive development of (consent) registrations and organ procurement suggests that the increased efforts in the area of continuous public education on organ donation and the shift to a strategy with cohesive multi-channel campaigns have paid off. Other studies support this view, identifying an interaction between donor education campaigns [36].

Nonetheless, the response to the mailing of registration forms in 2005 was much smaller than the response just after the introduction of the Act. Apparently, most of the people who could easily be convinced were already registered by then.

The mailings to age groups, of whom it is known that they are willing to donate, were relatively more successful. It is unknown whether and how other groups can be convinced to register. It has to be noted that the effects of measures aimed at religious groups on registration rates are unknown. This raises the question how to further increase the number of registrations and what number of registrations is a realistic target.

The diffuse correlation between donor education campaigns and donor procurement

The effects of multi-channel education campaigns on donor procurement are rarely reported; the correlation between the effects of education campaigns and donor procurement seems to be rather unclear.

In this study we found a strong positive correlation between donor procurement rates and (consent) registration rates. As other studies have shown that registered consent has a positive influence on the consent rates of next of kin [37–39], this confirms the importance of policy measures aimed at enlarging the donor register and increasing the number of explicit consent registrations within the framework of an explicit consent registration system.

When interpreting donor procurement rates it is important to keep in mind that they can fluctuate between years. The fluctuation in 2007 is often attributed to the nongovernment Big Donor Show of television network BNN. The monthly donation rates of that year [40], however, already showed a steady-increase months before the Big Donor Show was broadcast in June. As there were no changes to the legal or organizational system this raises the question whether there was already a sense of urgency regarding this issue in the Netherlands, and whether the Big Donor Show was simply an expression of that sense of urgency. This fluctuation could of course be just coincidental. For the time being, we do not have an explanation for this fluctuation, but in terms of the number of extra donors (20 extra donors – 10% of the total number of organ donors) the fluctuation was relevant. The fluctuation in 2007 indicates that the procurement rates of consecutive years should be taken into account when assessing the impact of policies on organ donation on a national level.

High rates of registered refusals?

As the enactment of the Donor Register 35% of the registered people refuse organ donation. Compared with other countries, this rate of registered refusals seems high [41]. However, unlike the Netherlands the governments of presumed consent countries do not have policy measures to encourage people to register. It

is therefore difficult to compare the Dutch refusal rates with the refusal rates of countries with a presumed consent country.

Strengths and limitations

Our strategy to describe and explain the impact of policy measures over time seems to be effective. The increases in (consent) registration rates and procurement rates could well be explained by the change to the government's policy on donor education and implemented policy measures.

A key limitation of the assessment of the impact of donor education on procurement rates is that other policy measures also have an effect on organ procurement. The plan of action on organ donation not only contained measures aimed at public education, but also measures designed to increase the donor pool [42] and optimize the procurement process in hospitals [22]. Furthermore, not all measures have been evaluated in the Netherlands; there is only limited data available on their effects. For example, for individual measures, data on the effects on consent rates, the distinction between areas (rural and metropolitan) or ethnic groups, or the influence of costs on effects is lacking.

Moreover, this study only highlights the Dutch situation. Other countries show trends in their donor procurement efficiency [17]. For many countries it remains unknown what causes these trends. Studying these trends using a similar method might reveal which policy measures are responsible for decreases and increases in donor registration and donor procurement.

CONCLUSIONS

This study gives insight into both the strategy of the Dutch government to increase and maintain positive public attitudes towards organ donation and the impact of this strategy on organ procurement. Evidently, it is important that governments explicitly support organ donation. For countries with an explicit consent system, it seems to be important to maximize the number of consent registrations, because of a high correlation with donor procurement rates [Pearson correlation = 0.80 ($P < 0.01$)].

Over time, a lot of effort was put into donor education. The message of the campaigns focussed more on convincing people to register consent, and multi-channel campaigns gained more cohesion. This change in the strategy of Dutch donor policy has paid off. Our study shows that trends in donor registration and donor procurement can be linked to the strenuous efforts made in the implementation of campaigns. But we also found some fluctuation in donor procurement between years which cannot be explained by the implementation of policy measures or changes in the organizational or legal system. Apparently, unknown mechanisms also have an impact on donor procurement.

Finally, despite increased efforts, the impact of mass media campaigns on registration rates decreases over time. The question remains whether the effects of policy measures will further level off and what donor registration rates and efficiency of donor procurement are realistic targets.

AUTHORSHIP

RC: study conception and design, data collection, wrote the paper. RDF: study conception and design. RDF, SKMG, GAB and JZ: critical revisions to the manuscript for important intellectual content and provided supervision. All the authors made substantial contributions to the analysis and interpretation of the data. All the authors read and approved the final manuscript.

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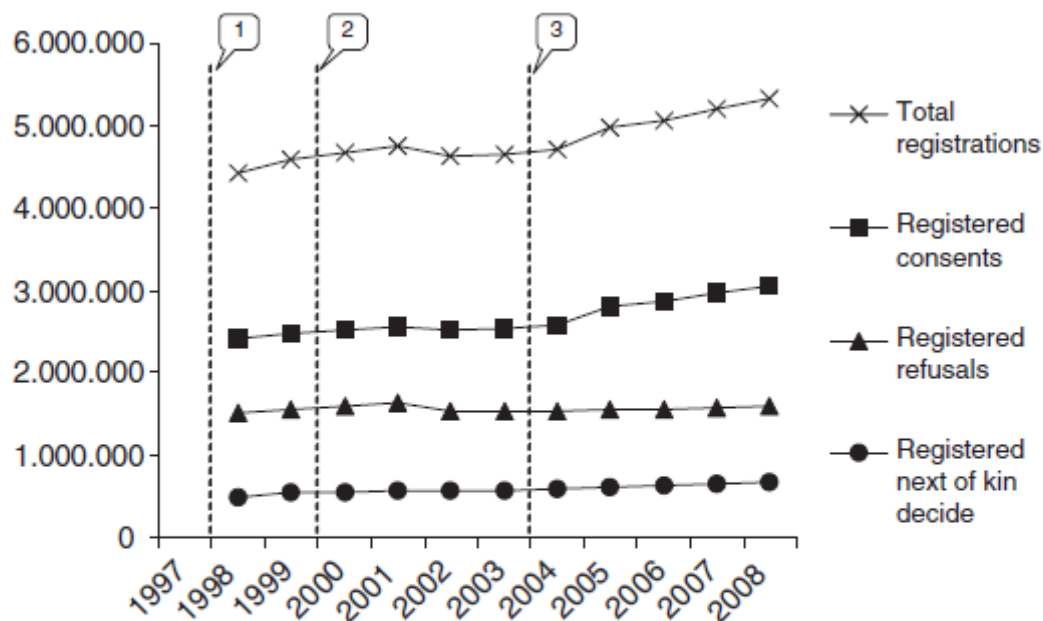
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FIGURES

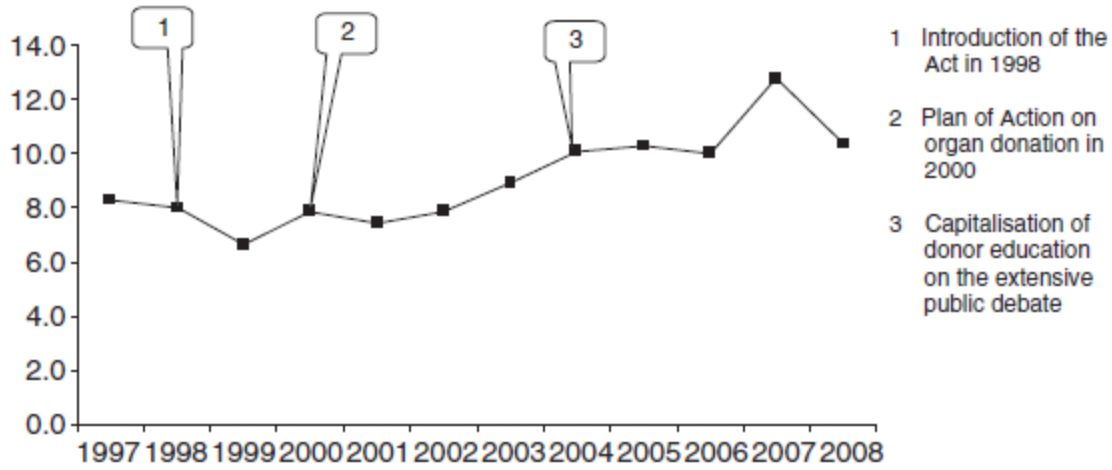
Figure 1 The number of registrations in the Dutch Donor Register (1998–2008).



- 1 Introduction of the Act in 1998
- 2 Plan of Action on organ donation in 2000
- 3 Capitalisation of donor education on the extensive public debate

Source: <http://www.donorregister.nl/organisatie/cijfers/registraties/keuze.aspx> (06-04-2008)

Figure 2 Donor procurement in the Netherlands shown by the donor rates adjusted for differences in relevant mortality rates between years (1997–2008).



Source: We obtained the relevant mortality rates for CVA and (traffic) accidents from Statistics Netherlands (www.cbs.nl) and the donation rates from the Dutch Society for Transplantation (www.transplantatiestichting.nl).