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## Cancer patients' trust as a motivator to seek a second opinion and its effects on trust

Marij A. Hillen<sup>a</sup> , Ellen M. A. Smets<sup>a</sup>, Jacqueline M. Stouthard<sup>b</sup> ,  
Filip Y. F. de Vos<sup>c</sup>  and Vicky Lehmann<sup>a</sup> 

<sup>a</sup>Department of Medical Psychology, Amsterdam Public Health, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands; <sup>b</sup>The Netherlands Cancer Institute (NKI), Amsterdam, The Netherlands; <sup>c</sup>Department of Medical Oncology, Cancer Center, University Medical Center Utrecht, Utrecht, The Netherlands

### ABSTRACT

**Objective:** Cancer patients may seek a second opinion (SO) driven by reduced trust in their own providers. Their trust may be diminished or reinforced through the SO. This study aimed to assess (1) what proportion of patients seek SOs motivated by lacking trust and how trust changes over time; (2) whether patients' trust differs by the outcome of the SO (i.e. similar/different opinion); and (3) how communication during the SO affects trust.

**Design:** A longitudinal mixed methods study including self-report assessments before ( $T_0$ ), immediately following ( $T_1$ ), and two months after the SO ( $T_2$ ). SO consultations ( $N=62$ ) were audio recorded, and patient-oncologist communication about the referring oncologist was coded.

**Main outcome measures:** Patient-reported motives and their trust in referring oncologists.

**Results:** Reduced trust motivated 21% of patients to seek a SO. Most patients criticised their referring oncologist. Consulting oncologists generally defended their colleagues, but such affirmation was unrelated to patients' subsequent trust. Over time, trust did not change substantially. Yet, it was restored in patients motivated by impaired trust, and remained low for patients receiving a different medical outcome.

**Conclusion:** Patients need support to more constructively discuss their treatment relationship. Oncologists need support in providing independent SOs without harming trust relations.

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Trust;  
patient-provider communication;  
second opinion;  
oncology;  
referral

## 1. Introduction

Second opinions (SOs) are initiated by cancer patients and/or oncologists to solicit a re-assessment of a proposed diagnosis or treatment plan by a second, independent specialist (Hillen, Medendorp, Daams, & Smets, 2017; Tattersall et al., 2009). Patients often do so in an effort to gather more information or explore additional (experimental) treatment options (Hillen, Medendorp, et al., 2017; Payne et al., 2014) to ultimately increase chances of survival and extend life. Cancer patients frequently

**CONTACT** Marij A. Hillen  [M.A.Hillen@amsterdamumc.nl](mailto:M.A.Hillen@amsterdamumc.nl)  Department of Medical Psychology, Amsterdam Public Health, Amsterdam UMC, University of Amsterdam, Amsterdam 1105 AZ, The Netherlands

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request SOs, but precise rates are difficult to assess and may vary widely depending on geographical and clinical context (Hillen, Medendorp, et al., 2017; Ruetters, Keinki, Schroth, Liebl, & Huebner, 2016). The utility of SOs has been extensively debated, particularly if SOs are requested by patients. Seeking a SO may yield peace of mind for patients and their family, but it may also impair the relationships with their providers, because requesting a SO could be interpreted as indicating mistrust in the treating oncologists' expertise (Axon, Hassan, Niv, Beglinger, & Rokkas, 2008). Moreover, SOs are inherently triadic, including the relationships of the patient with two different oncologists, as well as an interaction (i.e. over mail/phone) between the referring and consulting oncologist. This triadic nature of SOs can make them particularly sensitive for all involved parties (Greenfield, Pliskin, Wientroub, & Davidovitch, 2012), and concerns about trust, loyalty, and disrupted communication can play a significant role when patients seek SOs (Payne et al., 2014; Peier-Ruser & von Greyerz, 2018).

Trust is a central component of a positive patient-provider relationship, which entails that patients believe their provider will act in their best interests (Hall, Dugan, Zheng, & Mishra, 2001; Hillen, de Haes, & Smets, 2011). Cancer patients' strong trust in their treating oncologist could hold them back from requesting a SO, even if they may desire one. Indeed, research suggests that a primary reason to *not* seek a SO is ample trust and/or fear of jeopardising a positive relationship with the treating oncologist (O'Rourke, 1999; Payne et al., 2014; Peier-Ruser & von Greyerz, 2018). Conversely, mistrust in the treating oncologist's abilities and/or opinion could motivate patients to seek a SO. Some evidence indeed suggests that cancer patients who seek a SO have lower trust compared to those who do not (Gross, Hillen, Pfaff, & Scholten, 2017), and that about 24-38% of patients seeking a SO is motivated by dissatisfaction/interpersonal problems with their providers (Cecon, Hillen, Pfaff, Dresen, & Groß, 2019; Loehberg et al., 2020; Mellink et al., 2003; Philip, Gold, Schwarz, & Komesaroff, 2010; Tattersall et al., 2009).

Trust may not only facilitate or inhibit SO seeking, it could also be affected by it, depending on the medical outcome of the SO. If the first opinion is *confirmed*, it may reinforce patients' trust in the referring oncologist's competence. If the SO yields new/additional treatment options and thus *differs* from the first opinion, it may reduce trust in the referring oncologist. At the same time, the medical outcome (i.e. similar/different opinion) may affect patients' trust in the consulting oncologist who conducts the SO. A differing opinion may either enhance trust, for example because new treatment options provide hopeful prospects, or alternatively decrease trust in both medical specialists due to confusion about the discrepancy between both opinions (Axon et al., 2008; Moumjid, Gafni, Bremond, & Carrere, 2007; Okamoto, Kawahara, Okawa, & Tanaka, 2015).

Moreover, and depending on what happens *during* the SO consultation, patients' trust in both the referring and the consulting oncologist could either be strengthened or reduced (Cecon et al., 2019; Philip et al., 2010). However, research on how cancer patients' trust is affected by the SO *process* is scarce and longitudinal data is missing. In a previous survey study, the majority of cancer patients (56%) reported that their trust in the referring oncologist was improved after the SO (Fuchs et al., 2016). Similarly, referring oncologists reported in interviews that after back-referral, the relationship with their patients had strengthened (Hillen et al., 2018). Yet, prospective

research is needed to investigate how trust in both the referring and consulting oncologist is affected by the SO. Therefore, it is also essential to know how patients and providers communicate during SOs.

The scarce available evidence about the content of SO consultations is based on survey and interview data, and suggests that matters of trust and loyalty affect consulting oncologists' communication. Specifically, in interviews, oncologists reported being cautious when communicating about the referring oncologist with patients, or when talking to the referring oncologist directly (Hillen et al., 2018; Philip et al., 2010, Philip, Gold, Schwarz, & Komesaroff, 2011). They reported perceiving it as their responsibility to maintain the patients' relationship with the referring provider, while also not wanting to jeopardise their own professional relationship with the referring oncologist or to undermine the competencies of their colleagues. Sometimes, such interpersonal aspects even resulted in endorsing the referring oncologist's approach (i.e. first opinion) instead of emphasising small discrepancies, to avoid creating confusion or uncertainty for the patient (Hillen et al., 2018; Philip et al., 2011). Thus, how consulting oncologists discuss the referring oncologist may be crucial for patients' trust, but research to substantiate such effects is limited so far to physician self-report data.

In short, a lack of trust may motivate patients to seek a SO, and trust in both the referring and consulting oncologist may be affected by the SO itself and its medical outcome (i.e. by whether the first and second opinions are similar or different). Yet, empirical evidence is scarce and based on (retrospective) self-report. Prospective research is necessary to reduce recall bias. Moreover, it is essential to objectively assess communication during second opinion consultations, and relate it to self-reported experiences of both patients and oncologists. This can yield insights into *how* and *through which mechanisms* patients' trust may be changed by SOs.

Therefore, the aims of this study were threefold. First, we tested what proportion of patients seek a SO motivated by lacking trust in their treating (i.e. 'referring') oncologist, whether such motivation determines changes in trust over time, and whether referring oncologists accurately perceive patients' trust in them. Second, we tested whether and how the medical outcome of the SO (i.e. similar/different opinions) affects patients' trust in both oncologists. Third, we examined how communication during the SO consultation affects cancer patients' trust. For the latter aim, we specifically assessed to what extent and how the referring oncologist was discussed during the SO, expecting that higher rates of positive/confirming utterances made by the consulting oncologist (about their referring colleague) enhance patients' trust in the referring oncologist, while higher rates of critical utterances may reduce trust. Such knowledge could be used to further optimise SOs for patients and oncologists, for example by educating oncologists about these mechanisms and training their specific communication skills. Ultimately, this may also improve patients' well-being.

## 2. Materials & methods

### 2.1. Study design

Data presented here are part of a prospective mixed-methods study about SOs in oncology (SO-COM (Lehmann et al., 2020, 2021)), conducted in The Netherlands. The

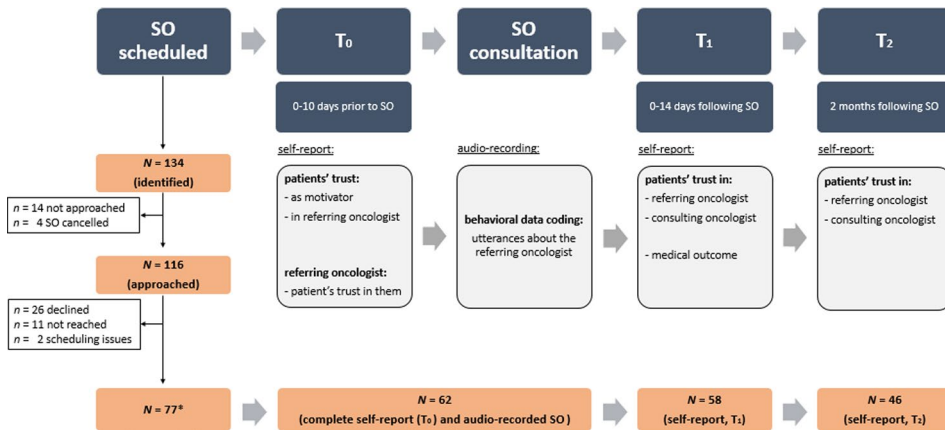
overall aim of the SO-COM study was to examine communication during SOs and its medical and psychological consequences for patients. The SO-COM study entailed surveys completed at multiple time points and by different stakeholders (i.e. patients, referring oncologists, and consulting oncologists), as well as audio recordings of SO consultations. Data were collected at the Medical Oncology departments of two Dutch tertiary referral centres. The Netherlands has universal healthcare, with mandatory basic insurance for all adults. Hospitals in the Netherlands are generally private non-profit foundations, and healthcare insurances are mostly non-profit companies (Götze, 2010). Second opinions are fully covered by insurance after referral by any physician. Oncological SOs in The Netherlands are most frequently conducted at tertiary referral centres. We deliberately included two different types of centres: one specialised adult oncology facility well-known internationally, and one academic medical centre with expertise in specific tumour types.

## 2.2. Recruitment and procedures

Medical oncologists at both participating centres were invited to participate and signed informed consent forms. After signing informed consent forms, their respective outpatient centre/trial office consecutively identified any new adult cancer patient scheduled for a SO, who had sufficient Dutch language proficiency. Outpatient centre/trial office workers initially approached patients for consent to be contacted by the study team. The study team contacted consenting patients by telephone and if patients expressed interest, they were mailed an information letter, informed consent form, and the first survey ( $T_0$ ), to be completed before the SO consultation. Additionally, patients were asked for permission to contact their referring oncologist. The SO consultation was audio-recorded by research staff (not present during the SO), and confidentiality was guaranteed at all times. Directly after the SO ( $T_1$ ), patients received their second survey to be completed within one week. Two months later ( $T_2$ ), they were mailed the third and final survey. If patients had agreed, the study team contacted their referring oncologist to ask for their participation in this study. Referring oncologists who agreed, signed informed consent forms and completed one brief survey around the time of the SO ( $T_0$ ; Figure 1).

## 2.3. Sample

A total of  $N=116$  eligible patients were approached, but  $n=26$  (22.4%) declined participation (e.g. due to feeling too sick/anticipating participation too burdensome),  $n=11$  could not be reached, and  $n=2$  could not be included due to scheduling issues. Thus, a total of  $N=77$  patients participated (response rate: 66.4%; 77/116) of whom  $n=72$  provided any self-report data (see Figure 1 for a more detailed overview). Of these 72 patients, self-report data at  $T_0$  were incomplete for 2 patients and audio recordings were missing from 8 patients, e.g. due to technical issues. Thus, complete self-report data at  $T_0$  together with audio recordings were available from  $N=62$  patients and constitute the sample of the present manuscript. Over time,  $n=58$  patients also provided complete self-report data at  $T_1$  and  $n=46$  at  $T_2$ .



**Figure 1.** Overview of the SO-COM study procedures and data used in the presented analyses.

These patients were seen by a total of 24 different *consulting* oncologists. Most oncologists ( $n = 16/24$ , 66.7%) consulted 1–2 patients each, whereas two oncologists saw seven patients each, and one saw a maximum of eight patients. *Referring* oncologists of  $n = 57$  patients were contacted and  $n = 19$  provided complete self-report data.

Included cancer patients ( $N = 62$ ) were 28–85 years old ( $M = 58.1$ ) at T<sub>0</sub>. Participating patients were predominantly female ( $n = 39$ , 62.9%), partnered/married ( $n = 55$ , 88.7%), and highly educated ( $n = 26$ , 41.9%). Most had been diagnosed with breast (32.2%) or gastrointestinal tumours (27.4%), which often constituted advanced disease stages ( $n = 54$ ; 87.1%). Time since primary diagnosis ranged from 1 month–31 years (Table 1).

## 2.4. Measures

### 2.4.1. Self-reported outcomes

**Trust motivation.** Based on a literature review (Hillen, Medendorp, et al., 2017), patients completed a list of various possible motivations to seek the SO at T<sub>0</sub>. They could select one or more of eight potential reasons. Three of these motivations were related to trust and the patient-provider relationship and were used in the present analyses, i.e. ‘I did not have enough trust in my referring oncologist’, ‘I was not on good terms with my referring oncologist’, and ‘I was doubting my diagnosis and proposed treatment plan’. Endorsing any or all of these three reasons were categorised as trust being a motivator to seek a SO (yes/no, hereafter labelled ‘trust motivation’). An overview of all other reported motivations has been reported elsewhere (Lehmann et al., 2020).

**Trust.** Patients reported their trust in both the *referring* oncologist (T<sub>0</sub>, T<sub>1</sub>, T<sub>2</sub>) and the *consulting* SO oncologist (T<sub>1</sub> and T<sub>2</sub>) using the Dutch version of the 5-item short form of the Trust in Oncologist Scale (TiOS-sf, Hillen, Postma, Verdam, & Smets, 2017). The original and short form of the TiOS have been tested extensively regarding their reliability, validity and factor structure in Dutch and English (Hillen, Koning et al., 2012; Hillen et al., 2013; Hillen, Postma, et al., 2017); underlining the unidimensional structure and excellent internal consistency ( $\alpha > .9$ ) of the TiOS-sf. Items state for

**Table 1.** Background characteristics of included patients (N=62) who provided complete self-report data at baseline and had their SO recorded.

|                                                     | Median; Mean (SD), range |
|-----------------------------------------------------|--------------------------|
| Age                                                 | 58.5; 58.1 (10.6), 28–85 |
| Months since (primary) diagnosis                    | 16.0; 48.9 (74.0), 1–372 |
|                                                     | <b>n (%)</b>             |
| Sex                                                 |                          |
| Female                                              | 39 (62.9%)               |
| Male                                                | 23 (37.1%)               |
| Relationship status                                 |                          |
| Partnered/ married                                  | 55 (88.7%)               |
| Single                                              | 7 (11.3%)                |
| Level of education                                  |                          |
| Low ( <i>none/lower level vocational training</i> ) | 20 (32.3%)               |
| Middle ( <i>medium level vocational training</i> )  | 16 (25.8%)               |
| High ( <i>college/university</i> )                  | 26 (41.9%)               |
| Type of diagnosis                                   |                          |
| Breast tumors                                       | 20 (32.2%)               |
| Gastrointestinal tumors                             | 17 (27.4%)               |
| Urogenital tumors                                   | 10 (16.1%)               |
| Melanoma                                            | 5 (8.1%)                 |
| Gynecological tumors                                | 5 (8.1%)                 |
| Other                                               | 5 (8.1%)                 |
| Tumor stage                                         |                          |
| Advanced                                            | 54 (87.1%)               |
| Early                                               | 8 (12.9%)                |

example ‘*Your doctor strongly cares about your health*’ and are answered on a 5-point Likert scale (1=‘*completely disagree*’ to 5=‘*completely agree*’). Item scores were averaged, resulting in a potential range of 1–5, and Cronbach’s alpha were high across all time points ( $\alpha = .899-.954$ ).

Referring oncologists reported their perceptions of their patients’ trust in themselves (at T<sub>0</sub>) using a visual analogue scale (VAS) ranging from ‘*no trust at all*’ to ‘*complete trust*’. This VAS was 10 cm wide and oncologists’ marks along the scale were measured and used as ranging from 0 to 10.

**Medical outcome.** At T<sub>1</sub>, patients completed a face-valid item assessing their perception of the SO outcome, asking: ‘*What was the medical outcome of your second opinion consultation?*’ with the following response categories: *the opinion of the oncologist conducting the second opinion was* (1) *completely the same*, (2) *largely the same*, (3) *largely different* or (4) *completely different compared to the first opinion*. These four response categories were dichotomised into ‘similar’ (1 and 2) versus ‘different’ (3 and 4) medical outcome of the SO.

#### 2.4.2. Observational data: communication about the referring oncologist

Coding of all audio-recorded consultations was performed in the ‘Observer XT 14’ software for observational analysis (Noldus, 1991). Interaction analysis is the method of choice when the research question(s) focuses on overt behaviour (Chorney, McMurtry, Chambers, & Bakeman, 2015). It entails directly observing, systematically coding and quantitatively analysing medical interactions, thus enabling the methodic investigation of actual behaviour rather than relying only on self-report (Bell & Kravitz, 2014; Bylund & Makoul, 2005). Although interaction analysis was traditionally primarily



used to *describe* what happens in interactions, it is additionally increasingly used to test theory-based hypotheses (Bell & Kravitz, 2014; Siminoff & Step, 2011). Within the Observer XT interface, a study-specific coding scheme with accompanying coding manual was developed to assess communication about SO-specific topics. For the present analyses, we focussed on codes assessing discussions about the referring oncologist (Supplement 1). To establish sufficient inter-rater reliability, two trained researchers independently coded  $n=20$  randomly selected SO recordings and compared their assessments after each recording to establish consensus. Inter-rater reliability on the timing and duration of SO-specific intervals was  $\kappa = .94$ , and  $\kappa = .48$  across the fully detailed coding scheme. All remaining recordings ( $n=49$ ) were assessed by one researcher (for the full coding scheme and its development see (Lehmann et al., 2021) or contact the corresponding author).

In all consultations, intervals were marked in which the referring oncologist was discussed. Within each interval, utterances were coded as (a) statements, (b) actions, or (c) characteristics of the referring oncologist, (d) the relationship between the patient and referring oncologist, or (e) the relationship between the referring and consulting oncologists (see Supplement 1). The valence of each of these utterances was specified as critical (e.g. 'Doctor X didn't really explain anything'), neutral (e.g. 'I will discuss this with doctor X'), or positive (i.e. confirming/defending; e.g. 'The treatment doctor X gave you –we would have done the same'). Additionally, we marked any open or closed questions about the referring oncologist posed by the consulting oncologist. Questions posed by the patient were also coded, along with the initial reaction of the consulting oncologist (e.g. ignore, acknowledge, explore, provide information; see Supplement 1).

Coded data were used to calculate the duration and percentage of time spent discussing the referring oncologist relative to the total consultation time. We calculated the proportion of how often patients and consulting oncologists uttered critical or positive content about the referring oncologist (relative to their total number of utterances about the referring oncologist).

## 2.5. Statistical analyses

A-priori power calculations were performed to assess the ability to detect changes over time. Based on power analysis prior to data collection for the full SO-COM study, a repeated measures ANOVA with three time-points, including between-within interactions (80% power,  $\alpha=.05$ , relatively small effect size of .20), a sample size of  $N=42$  would be required (Cohen, 1988). To account for possible clustering effects within oncologists who provided several SOs, we estimated a design effect ( $D_{\text{eff}}$ ) of 1.6 based on  $D_{\text{eff}} = 1 + (m - 1) \cdot \text{ICC}$ , where  $m$  is the estimated number of recordings per oncologist (i.e.  $m=4$ ) and intra-class correlation (ICC) is .2 (Hillsdale, 1987). Thus, our required  $N$  was 67 (i.e.  $N=42 \cdot 1.6$ ), which we almost reached. Clustering effects within oncologists were checked by using t-tests to compare consultation duration and trust scores of the three oncologists who saw multiple patients versus all other consulting oncologists, which indicated no differences ( $p$ -values  $>.3$ ). Hence, we decided it was appropriate to proceed without multilevel analyses/nested models.



Addressing aim 1, descriptive statistics are presented for trust-related motivations, and differences in trust scores over time were tested using a repeated measures ANCOVA, i.e. covarying for trust motivations. Associations between patient- and referring oncologist-reported trust scores were tested using Pearson's correlation analyses. For aim 2, differences in trust after the SO ( $T_1$ ) between patients who got a different vs. similar medical outcome were assessed using t-tests. Addressing aim 3, descriptive statistics were used to present the duration spent discussing the referring oncologist and ratios of critically, positively, and neutrally valenced utterances. Pearson's correlations were used to test associations between the amount of critical or positive utterances during the SO with trust in the referring and consulting oncologists directly following the SO ( $T_1$ ).

### 3. Results

#### 3.1. Trust as motivator, its development over time, and oncologist perceptions (Aim 1)

Of all patients, 21.0% ( $n=13$ ) indicated that aspects related to trust in their referring oncologist motivated them to seek a SO, which included doubting the first opinion ( $n=11$ ), a negative relationship ( $n=3$ ), and/or not trusting the referring oncologist ( $n=2$ ). Patients' trust scores in the referring oncologist before the SO ( $T_0$ ) were on average 3.9 (potential range 1–5; Table 2). Patients who indicated trust-related motivations scored significantly lower ( $M=3.2$ ) than the remaining patients ( $M=4.2$ ,  $t(60)=3.528$ ,  $p=.001$ ,  $d=1.10$ , Table 2). More importantly, trust developed differently over time between those two groups (Hotelling's  $T=.193$ ;  $F(2, 43)=4.153$ ,  $p=.022$ ). Although significantly different before the SO ( $T_0$ ), trust in the referring oncologist was increased throughout the SO process ( $T_1$ ) among patients motivated by impaired trust, and trust levels were similar between both groups at  $T_2$  (Figure 2).

Participating referring oncologists ( $n=19$ ) believed that their patients had high trust in them ( $M=7.8$ , potential range 0–10; Table 2). Their perceived trust scores at  $T_0$  were not correlated with patient-reported trust scores at any time point (all  $r_p$ -values  $<.4$ ;  $p$ -values  $>.1$ ).

#### 3.2. Medical outcome of the second opinion as predictor of trust (Aim 2)

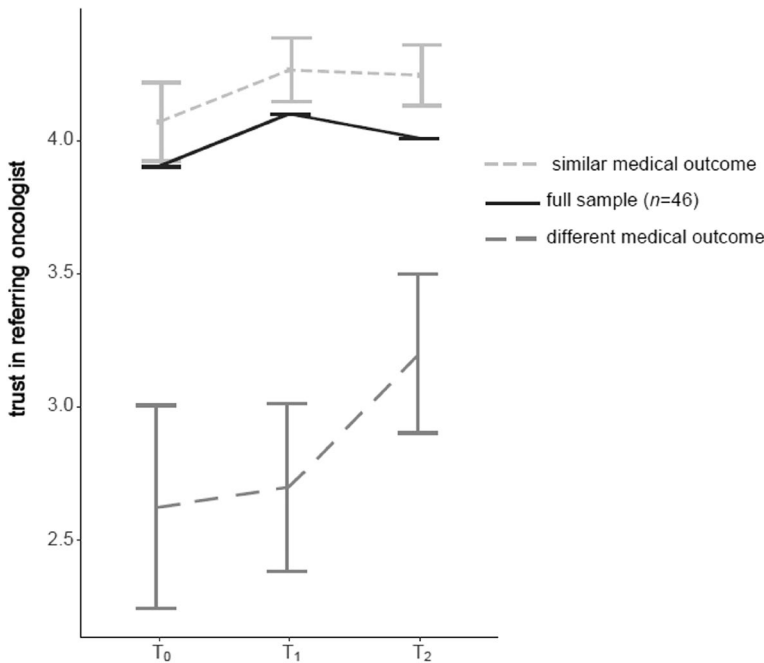
Patients' trust in the referring oncologist also differed by the medical outcome of the SO immediately following the SO ( $T_1$ ). Patients who reported their SO confirmed the first opinion (i.e. similar medical outcome,  $n=52$ ), reported much higher trust in their referring oncologist than the 6 patients who got a different opinion ( $M=4.3$  vs. 2.7,  $t(56) = 4.69$ ,  $p < .001$ ,  $d=2.0$ , Table 2). To check whether patients who reported receiving a different SO generally experienced lower trust, a repeated measured ANOVA tested whether trust scores developed differently for patients who received a different vs. similar SO. Trust scores did not change differently between groups (Hotelling's  $T = .061$ ;  $F(2, 43) = 1.303$ ,  $p = .282$ ), but both patient groups significantly differed from each other at all times ( $F(1, 44) = 26.295$ ,  $p < .001$ ; Figure 3). Patients who received a different medical opinion reported lower trust in the referring oncologist at all times points, but caution is advised given the small sample size (Table 2,

**Table 2.** Trust in the referring and consulting oncologists over time

|                                                            | T <sub>0</sub><br>M(SD), range    | T <sub>1</sub><br>M(SD), range    | T <sub>2</sub><br>M(SD), range | Comparison                           | p     |
|------------------------------------------------------------|-----------------------------------|-----------------------------------|--------------------------------|--------------------------------------|-------|
| <b>Patients:</b>                                           | N=62                              | n=58                              | n=46                           |                                      |       |
| <b>trust in referring oncologist</b>                       | 3.9 (1.0), 1.0 – 5.0              | 4.1 (0.9), 1.8 – 5.0              | 4.0 (0.9), 1.0 – 5.0           | F <sub>time</sub> (1,45)=1.96        | .168  |
| <b>trust in referring oncologist by trust motivations:</b> |                                   |                                   |                                | F <sub>group</sub> (1,44)=8.15       | .007  |
| motivated by lacking trust (n=13) <sup>#</sup>             | 3.2 (1.1), 1.0 – 5.0 <sup>a</sup> | 3.5 (1.1), 1.8 – 5.0              | 4.0 (1.0), 2.4 – 5.0           | F <sub>time*group</sub> (1,44)=7.89  | .007  |
| not motivated by lacking trust (n=49) <sup>#</sup>         | 4.2 (0.9), 1.0 – 5.0 <sup>a</sup> | 4.3 (0.8) 1.8 – 5.0               | 4.1 (0.9), 1.0 – 5.0           | F <sub>group</sub> (1,44)=7.11       | .011  |
| <b>trust in referring oncologist by medical outcome:</b>   |                                   |                                   |                                | F <sub>time*group</sub> (1,44)=26.30 | <.001 |
| similar medical outcome (n=52) <sup>#</sup>                | 4.1 (0.9), 1.0 – 5.0              | 4.3 (0.8), 2.0 – 5.0 <sup>b</sup> | 4.2 (0.6), 2.4 – 5.0           | F <sub>time</sub> (1,44)=2.41        | .128  |
| different medical outcome (n=6) <sup>#</sup>               | 2.6 (1.0), 1.0 – 3.4              | 2.7 (0.9), 1.8 – 4.0 <sup>b</sup> | 3.2 (1.1), 2.0 – 5.0           | F <sub>time*group</sub> (1,44)=0.69  | .412  |
| <b>trust in consulting oncologist</b>                      |                                   |                                   |                                | t(45)=2.06 <sup>c</sup>              | .045  |
| <b>Referring oncologists:</b>                              |                                   |                                   |                                |                                      |       |
| perceived patients' trust in them                          | –                                 | 4.4 (0.7), 1.2 – 5.0              | 4.3 (0.6), 2.8 – 5.0           |                                      |       |
| for n=19 patients                                          |                                   |                                   |                                |                                      |       |
| 7.8 (1.1), 6 – 10                                          |                                   |                                   |                                |                                      |       |

Note. Descriptive statistics are reported for all patients included at each time point (N=62, 58, and 46 respectively), whereas F-tests are automatically based on patients with complete data across all time points (i.e., n=46);

<sup>#</sup> refers to N at T<sub>0</sub> (of the smaller group n=9/13 were retained by T<sub>2</sub>); <sup>#</sup> refers to N at T<sub>1</sub> (n=6/6 were retained by T<sub>2</sub>); <sup>a</sup> these descriptive statistics refer to n=62 participants who completed T<sub>0</sub> with t(60)=3.53, p=.001, d=1.10 accordingly. Please note that observed descriptive statistics of completers at all times (n=46) were M=4.1 (0.9) vs. M=2.9 (1.2), d=1.26; <sup>b</sup> descriptive statistics refer to n=58 participants who completed T<sub>1</sub> with t(56)=4.69, p<.001, d=2.02, note that observed statistics of completers (n=46) were M=4.3 (0.7) vs. M=2.7 (0.9), d=2.06; <sup>c</sup> paired samples t-test is based on patients' scores who completed both T<sub>1</sub> and T<sub>2</sub> (n=46), thus comparing M=4.5 (0.6) vs. M=4.3 (0.6), d=0.31;



**Figure 2.** Estimated marginal means for trust scores among patients who were and those who were not motivated by impaired trust in the referring oncologist; and observed means for the full sample with complete data over time from T<sub>0</sub> (before the SO), T<sub>1</sub> (following the SO), to T<sub>2</sub> (2 months later).

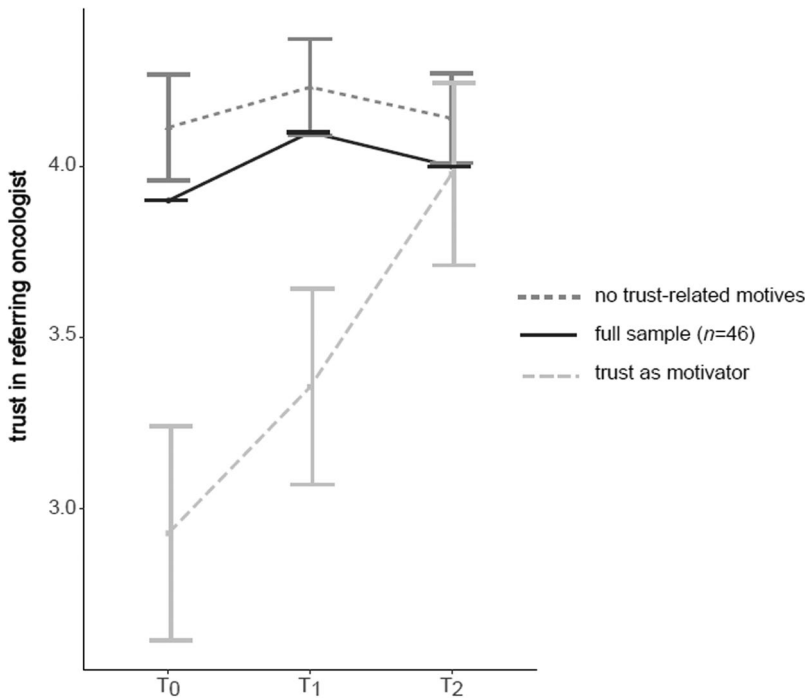
**Table 3.** Communication about the referring oncologist across all 62 SOs

|                                                  | patient<br><i>n</i> = 1009 | consulting oncologist<br><i>n</i> = 867 |
|--------------------------------------------------|----------------------------|-----------------------------------------|
| <b>Utterances about the referring oncologist</b> |                            |                                         |
| Critical                                         | <b>519, 51.4%</b>          | 112, 12.9%                              |
| Neutral                                          | 248, 24.6%                 | 115, 13.3%                              |
| Confirming/defending                             | 242, 24.0%                 | <b>640, 73.8%</b>                       |
| <b>Critical utterances about:</b>                |                            |                                         |
| Actions                                          | <b>234, 45.1%</b>          | <b>68, 60.7%</b>                        |
| Statements/remarks                               | 170, 32.8%                 | 29, 25.9%                               |
| Characteristics                                  | 59, 11.4%                  | 1, 0.9%                                 |
| Relationship with patient                        | 53, 10.2%                  | 13, 11.6%                               |
| Relationships with consulting oncologist         | 3, 0.6%                    | 1, 0.9%                                 |
| <b>Positive utterances about:</b>                |                            |                                         |
| Actions                                          | <b>79, 33.1%</b>           | <b>328, 51.3%</b>                       |
| Statements/remarks                               | <b>80, 32.6%</b>           | 156, 24.4%                              |
| Characteristics                                  | 37, 15.3%                  | 79, 12.3%                               |
| Relationship with patient                        | 42, 17.4%                  | 15, 2.3%                                |
| Relationships with consulting oncologist         | 4, 1.7%                    | 62, 9.7%                                |

Note. <sup>a</sup> *n* = 2 patients did not say anything about their referring oncologist

Figure 3). Note that interaction effects between trust as motivator and medical outcome could not be tested as only two patients who were motivated by lacking trust also received a different SO.

Following the SO (T<sub>1</sub>), patient-reported trust scores in the consulting oncologists were high (*M* = 4.4; potential range 1–5), and did not differ by whether patients had received a different or similar medical opinion (*M* = 4.3 vs. 4.4, *t*(56) = 0.194, *p* = .847).



**Figure 3.** Estimated marginal means of trust scores among patients who received a similar vs. different second opinion; and observed means for the full sample with complete data over time from T<sub>0</sub> (before the SO), T<sub>1</sub> (following the SO), to T<sub>2</sub> (2 months later).

### 3.3. Observed communication about the referring oncologist (Aim 3)

The total duration of the 62 audio-recorded SO consultations ranged between 19 and 72 minutes ( $M=40$ ). On average, 12.6% of the time (i.e. <5 minutes) was spent discussing the referring oncologist, which ranged from 1–39% of the whole consultation time (i.e. 15 seconds–12 minutes). All but  $n=2$  patients talked about their referring oncologist/primary care team. Out of all patient utterances about the referring oncologist ( $n=1009$ ), 51.4% were critical, 24.6% were neutral, and 24.0% were positive (Table 3). Patients' critical utterances ( $n=519$ , 51.4%) were most commonly about the referring oncologist's actions ( $n=234/519$ , 45.1%) or statements/remarks ( $n=170/519$ ; 32.8%; Table 3).

In contrast, most consulting oncologists' utterances about the referring oncologist/care team were positive (i.e. confirming/defending,  $n=640/867$ , 73.8%), which most often included confirming or supporting the actions of the referring oncologist/team ( $n=328/640$ , 51.3%; Table 3). Patient critical and oncologist confirming utterances were not correlated ( $r_p = .142$ ,  $p = .272$ ), but this was distorted by three outliers (i.e.  $n=3$  patients with a high amount ( $n > 30$ ) of critical comments). If removed, the correlation was significant ( $r_p = .381$ ,  $p = .003$ ) suggesting that increased patient criticism and increased oncologist confirmations were somewhat related.

Patients who were motivated by lacking trust ( $n=13$ ) made considerably more critical statements about their referring oncologist than other patients ( $M=17.0$  vs.

6.1,  $t(60) = -3.863$ ,  $p < .001$ ,  $d=1.2$ ), and had a higher proportion of critical talk (relative to neutral and positive statements;  $M=55.8\%$  vs.  $37.5\%$ ,  $t(58) = -2.171$ ,  $p = .034$ ,  $d=0.7$ ).

The more patients criticised their referring oncologist during the SO consultation, the lower their reported trust in them following the SO at  $T_1$  ( $r_p = -.346$ ,  $p = .008$ ;  $r = -.476$ ,  $p < .001$  without the three outliers). However, the amount of criticising remarks was unrelated to their trust in the consulting oncologist (irrespective of outliers;  $r_p = -.139$ /. $-.177$ ,  $p > .2$ ). Interestingly, the amount of confirming utterances by the consulting oncologist was also unrelated to patient trust scores in either oncologist following the SO ( $r_p$ -values  $< .14$ ,  $p$ -values  $> .3$ ).

## 4. Discussion

### 4.1. Discussion of findings

This study examined trust as a motivator to seek a second opinion (SO) in medical oncology and how trust is affected by communication during and by the outcome of the SO. Less than a quarter of patients sought a SO due to insufficient trust and for these patients, trust in the referring oncologist was restored after the SO. Overall, trust levels remained relatively stable over time, but patients who received a different medical opinion were less trusting throughout all time points. During the SO consultation, patients tended to express criticism of their referring oncologist/care team, whereas consulting oncologists mostly supported and defended them. Yet, it appeared that more reinforcing statements from the consulting oncologist did not increase trust among patients. The present findings are essential to cancer patients' and survivors' well-being, given that SOs can affect patients' relationships with their treating specialists and the course of their further cancer treatment.

This study found trust-related issues as motivator for SOs somewhat less frequently than other studies, which reported rates of 24–38% (Cecon et al., 2019; Loehberg et al., 2020; Mellink et al., 2003; Philip et al., 2010; Tattersall et al., 2009). A particularly small proportion of our sample (8%) specifically reported to be motivated by an actual impaired relationship or lack of trust in their referring oncologist. This discrepancy with earlier findings may be explained by our study setting in medical oncology, involving mostly patients with advanced cancer stages who may have different needs than patients with early-stage cancer, who made up the majority of participants in most previous studies. For example, patients treated with curative intent may seek a SO mainly to choose between treatment options and to receive the best possible care provided by clinicians they feel they can fully trust. In contrast, advanced cancer patients may be primarily driven by their need to exhaust all options, hope of receiving a more promising prognosis, and/or any additional treatment options to further extend life (Lehmann et al., 2020). Many of these patients will have established long relationships with their oncologists, which is why a lack of trust may not be a driving motivator for them to request a SO. Nevertheless and although trust in the referring oncologist was adequate, it was not as high as reported in previous observational studies among cancer patients outside the SO setting (Hillen, Koning et al., 2012; Hillen, Postma, et al., 2017). This suggests that trust in this sample of SO seekers was

somewhat weaker than among cancer patients in general, and underlying reasons remain to be tested.

Referring oncologists' perceptions of their patients' trust in themselves was relatively high. However, their perceptions were unrelated to patients' reported trust in them, which is in line with previous findings (Coran, Koropecjy-Cox, & Arnold, 2013). Oncologists may not always be fully able to assess patients' experiences of their mutual relationship, possibly due to time constraints, being not fully aware of patients' goals and motives, or because they may generalise their perceptions based on (previous) experiences with other patients (Coran et al., 2013). Oncologists referring patients for a SO may need to more actively explore whether patients experience any interpersonal or trust-related problems. If they can address such concerns directly, this may even reduce patients' perceived need for an SO.

Across the whole group of patients, trust in the referring oncologist remained stable over time. This is surprising in light of previous studies in which both patients and referring oncologists reported increased trust after the SO (Goldman et al., 2009; Hillen et al., 2018). However, previous findings were all based on retrospective reports and may be influenced by recollection bias and/or a need to avoid cognitive dissonance. For example, patients may have retrospectively felt a need to believe that seeking a SO was worth the effort, which positively coloured their reported trust in the treating care team. Another potential contributing factor for stable trust scores over time may be that impaired trust was not a crucial motivating factor for most patients to begin with. This idea is supported by our finding that the subset of patients who *were* motivated by impaired trust indeed showed the expected pattern of restored trust levels after the SO consultation. Thus, in samples including more patients motivated by impaired trust, SO consultations may result in a steep increase in patients' trust.

Trust in the referring oncologist was low among patients who received a SO discrepant from the first opinion. This seems intuitive given that new insights may further undermine or question the first opinion, which also aligns with previous findings (Cecon et al., 2019). Interestingly, trust among these patients was lower throughout the entire SO process, as they have been more critical from the start. Underlying reasons remain speculative, but patients' a priori lack of trust may have affected their perception of the second opinion. This could have resulted in a higher likelihood of perceiving a discrepancy between the first and second opinion. Alternatively, these patients' medical situations may have been more complex, resulting in ambiguity among both the referring and consulting oncologists' opinions. If patients perceived such uncertainty, it may have reduced their trust in their treating oncologists beforehand. However, these results should be cautiously interpreted, as our study included only a small subsample of patients who received a different SO, which may be higher in other (less advanced) cancer populations (Heeg et al., 2019). For clinical practice, it is important to note that if patients are referred back after the SO with a different opinion/advice, it may be problematic for the relationship with their treating oncologist, as well as the adherence to and effectivity of their treatment (Cecon et al., 2019). Thus, additional prospective research in different and larger subsamples is needed to assess how trust is affected by the SO, how it can be successfully restored, and how it further develops over time after a back-referral.

Interestingly, although relatively few patients endorsed impaired trust in their referring oncologist before the SO, most expressed extensive criticism during the SO. Apparently patients were sometimes hesitant, unaware, or unable to clearly report their suboptimal relationship and trust in a survey. It may be that patients felt dependent on their referring oncologist and, therefore, feared that 'formally' acknowledging a lack of trust might jeopardise their treatment relationship (Hillen, Onderwater, Van Zwieten, de Haes, & Smets, 2012). Yet, the emotionally-laden situation of the SO itself (e.g. desperately hoping to hear something different) may drive patients to more 'informally' discuss any dissatisfaction with the consulting oncologist.

Patients' frequent criticism of their referring oncologists during the SO consultation was countered by supportive and defending remarks of the consulting oncologist about their referring colleagues. This supports previous self-reported findings, where oncologists indicated to deliberately support their colleagues' opinion during SOs, with the aim of strengthening the patient's relation with the referring oncologist (Hillen et al., 2018; Philip et al., 2011). Oncologists conducting the SO may be aware that discrepancies between medical opinions could be anxiety provoking among patients, as they may feel caught between two oncologists (McDaniel et al., 2013). Oncologists' consciousness of the triadic nature of these SO consultations may extend to their own relationship with their colleague, and in that way affect their behaviour (Philip et al., 2010). Interestingly, a study in regular medical consultations in oncology found that oncology specialists frequently criticised their colleagues, even when patients reported being satisfied with the care they had received (McDaniel et al., 2013). Thus, oncologists conducting SOs may utter less criticism due to the nature of SOs. However, by using this rather 'diplomatic' approach and supporting their colleagues' opinion, the independent nature of SOs may be at risk (Tattersall, 2011). Accordingly, a previous study utilising surveys among oncologists reported that they felt influenced by their own relationship with the referring oncologist (38%) and by their awareness that the SO report would be relayed to their colleagues (42%, Philip et al., 2011). More than half reported they would modify their recommendations based on the first opinion. Given these inherent interpersonal challenges of SOs, awareness should be raised that SOs should lead to optimal care and differing opinions should not be ignored solely as a means to avoid potential conflict (Tattersall, 2011).

#### **4.2. Strengths and limitations**

This is the first study to prospectively link communication in SOs and patients' trust, whereby some strengths and limitations need to be considered. Our initial response rate was adequate (66.4%), although selection bias may always be indicated. The sample included a rather large amount of higher educated patients, which is, however, representative of SO seekers. Moreover, the baseline sample ( $N=62$  patients) was adequate for the used statistical and observational analyses, but completion rates of patient self-report measures decreased over time, partly due to patients' deteriorating health conditions. This potentially introduces selection bias to the extent that the sickest, and potentially most vulnerable, patients dropped out of this study. Nevertheless, this study demonstrates the feasibility of conducting such studies in advanced cancer patients and may serve as encouragement for larger prospective



studies in the future. Moreover, the number of included referring oncologists was very limited ( $N=19$ ). Future studies should aim for larger samples of providers to enable more detailed analyses and comparisons. Another limitation is our suboptimal inter-rater agreement (Kappa) for specific communication behaviours of .48 across the full coding scheme, which is considered fair/moderate by some (Cicchetti, 1994; Landis & Koch, 1977) and even unacceptable by other (Krippendorff, 2018). It should be noted that high interrater reliability is seldom achieved in observational analyses targeting complex behaviours like patient-provider communication (Eide, Quera, Graugaard, & Finset, 2004). Moreover, our inter-rater reliability for overarching intervals was excellent (.94). Strengths of this study were the different perspectives captured in our data, which enabled us to compare the experiences of different stakeholders. Moreover, our behavioural analyses of audio-recorded SOs enabled us to provide real-life insights into communication during SO consultations. This is an important asset, as most previous SO research is retrospective and/or relying on self-report only, limiting the ability to explain potential effects. Moreover, additional research is needed to address effects of SOs on patients' well-being, future care, and survivorship issues.

### **4.3. Implications for practice**

In clinical practice, consulting oncologists should be supported in providing a maximally independent SO without harming patients' trust in the referring oncologist or their own relationship with colleagues. Patients' extensive criticism about the referring oncologist during the SO suggests that both patients and oncologists may need support in more constructively discussing patients' treatment relationship with providers during a SO. Particularly, if a negative relationship with their referring oncologist motivated the SO request, patients should be explicitly invited to more effectively discuss this during the SO. In other words, consulting oncologists could facilitate patients in discussing not only a medical plan, but also strategies for patients' future communication with their referring oncologist. This may enable patients to focus on future needs (e.g. how to better communicate wishes and needs with the referring oncologist) instead of dwelling in (negative) past events. Eventually, this might also lead to more effective use of oncological SOs.

## **5. Conclusion**

To conclude, we found that rather few patients seeking a SO in medical oncology reported being motivated by a lack of trust in their referring oncologist. Trust remained stable overall, but it appeared to be affected by the SO for some patients: Trust was restored for patients motivated by impaired trust, whereas it was reduced for patients receiving a discrepant second opinion. Patients' perception of provider competence is a key component of trust, which may be reduced as a result of a discrepant opinion (Hillen, Koning et al., 2012; Hillen, Onderwater, et al., 2012). Patients and oncologists may need support in more constructively discussing trust during a SO, to enhance better use of SOs in oncology.

### **Disclosure statement**

All authors, except F.Y.F. de Vos, declare no conflict of interest. Dr. de Vos received personal grants from Roche and AbbVie, which are however independent of this work.

## Institutional review board statement

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the institutional medical ethics review board of the study contractor (Amsterdam University Medical Centers, NL63087.018.17; study number 2017\_271) and the local review boards of both participating hospitals.

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## Notes on contributors

**Marij Hillen** is an assistant professor in Medical Communication. Her research focus is on interpersonal trust between clinicians and patients, and on uncertainty in medicine. She was trained as a psychologist. Twitter: @marijhillen. LinkedIn: <https://www.linkedin.com/in/marij-hillen-42732412/>

**Ellen Smets** is a professor of Medical Communication, with a focus on information provision between clinicians and patients. She was trained as a psychologist. ORCID: 0000-0002-8145-8595.

**Jacqueline Stouthard** is a medical oncologist specialised in the treatment of breast and gynecological cancers. She has recently become medical director at The Netherlands Cancer Institute–Antoni van Leeuwenhoek, a comprehensive tertiary cancer centre.

**Filip de Vos** is a medical oncologist specialised in the treatment of primary brain tumours, with extensive experience in conducting clinical trials.

**Vicky Lehmann** is a senior researcher in psycho-oncology. She is specialised in oncofertility and psychosocial issues of young adult cancer survivorship (e.g. psychosexual development, dating/romantic relationships, sexual health). LinkedIn: <https://www.linkedin.com/in/vicky-lehmann-ba864929/>

## ORCID

Marij A. Hillen  <http://orcid.org/0000-0001-5724-7934>

Jacqueline Stouthard  <http://orcid.org/0000-0002-7613-3788>

Filip Y. F. de Vos  <http://orcid.org/0000-0002-9082-5991>

Vicky Lehmann  <http://orcid.org/0000-0003-4898-3176>

## Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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