# **BMJ Open** Study protocol of OncoTolk: an observational study on communication problems in language-mediated consultations with migrant oncology patients in Flanders (Belgium)

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### ABSTRACT

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Dr. Demi Krystallidou; demi.krystallidou@kuleuven. be and Dr. Peter Pype, MD; peter.pype@ugent.be **Introduction** Effective doctor-patient communication in oncology settings can be challenging due to the complexity of the cancer disease trajectory. The challenges can become greater when doctors and patients do not share a common language and need to rely on language mediators. The aim of this study is to provide evidencebased recommendations for healthcare professionals, patients and language mediators on how to interact with each other during language-mediated consultations in oncology settings.

**Methods and analysis** A systematic review of the literature on communication problems in monolingual and multilingual oncology settings will be conducted. Thirty language-mediated consultations with Turkish-speaking or Arabic-speaking cancer patients, language mediators and Dutch-speaking oncologists/haematologists will be video-recorded in three urban hospitals in Flanders, Belgium. All participants will be interviewed immediately after the consultation and 2 weeks after it by means of video-stimulated recall. Multimodal interaction analysis will be combined with qualitative content analysis to allow for the identification of communication practices when communication problems occur.

Ethics and dissemination The study has been approved by the following ethics committees: Ghent University Hospital, Antwerp University Hospital, Antwerp Hospitals Network (ZNA). Results will be published via (inter)national peer-reviewed journals and the findings of the study will be communicated using a comprehensive dissemination strategy aimed at healthcare professionals, patients and language mediators.

### INTRODUCTION

Effective doctor-patient communication is an indicator of quality of care positively affecting adherence to treatment, the rate of recovery, as well as health outcomes and patient wellbeing.<sup>1-7</sup> Conversely, poor or ineffective communication can lead to a decrease in patients' understanding, an increase in anxiety or feelings of uncertainty, poorer compliance

### Strengths and limitations of this study

- This study will report on communication problems in language-mediated consultations in oncology settings, as documented in the literature and as they occur in the clinical practice.
- The complementary methodologies that will be applied allow for a novel and fine-grained analysis of communication problems.
- Generalisability of findings to other languages and contexts should be carefully considered.

with treatment and lower general satisfaction with care.<sup>6 8–10</sup> In oncology settings, due to the complexity of the cancer disease trajectory (eg. disclosure of diagnosis, proposal of treatment plan, patient's emotional experience), effective doctor–patient communication (often including family members) can be challenging.<sup>11–15</sup>

Due to the rising migration rates (258 million international migrants in 2017),<sup>16</sup> growing numbers of patients in many parts of the world do not share a common language with their healthcare provider and vice versa.<sup>17</sup> Language discordance between healthcare professionals and patients might result in communication problems<sup>18</sup> at the level of interaction during the medical encounter, which, by extension, can lead to misunderstandings regarding diagnosis, prognosis and treatment, might impede building a doctor–patient relationship of trust and might, at times, even lead to experiences of discrimination.<sup>19–23</sup>

In a bid to to overcome language barriers and prevent communication problems, family members, friends and healthcare staff who are fluent in the language of the host healthcare system translate for patients and

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doctors. Although the contribution of these ad hoc interpreters might be crucial, the use of trained professional interpreters is recommended,<sup>24</sup> yet it does not guarantee communication without problems either, such as the erroneous translation of medical terms.<sup>25</sup>

While studies have provided some evidence of communication problems arising from language discordance at the level of interaction,<sup>18,26–30</sup> the literature points out that there is still a wide range of communication problems that needs to be explored.<sup>31–34</sup> Particularly in oncology settings, the types of communication problems that arise from language barriers between patients and doctors, the ways in which they occur in the doctor–patient interaction, the reasons underlying these problems, as well as their effect on the doctor–patient communication remain largely under-investigated.

In this study, we focus on (1) the occurrence of communication problems arising from language discordance between healthcare professionals and patients at the level of interaction, (2) the ways in, and the reasons for, which these communication problems occur at the level of interaction, as well as (3) the effects of these processes on interaction and co-construction of understanding among patients, healthcare professionals and language mediators during the delivery of care.

We do not touch on participants' communication skills, namely their ability to communicate well. Instead, we depart from (1) the participants' inability to communicate with each other as a result of the language discordance between them and (2) the interactional complexity that is introduced through the presence of a language mediator.

### **Study objective**

The primary objective of this study is to provide a set of evidence-based recommendations for healthcare professionals, patients, carers and language mediators in oncology settings on how to interact with each other in language-mediated consultations. The recommendations will hopefully allow them to improve their own communication practices in interaction with each other, contributing in this way to the elimination of communication problems and to the optimisation of the provision of care in oncology settings.

Accompanying the study objective, the goals of the study are:

- 1. To identify communication problems in languagemediated consultations in oncology settings, as currently recorded in the existing literature (WHAT).
- 2. To gain practice-based insights into the interactional and communicative processes and semiotic resources which participants in consultations employ (HOW).
- 3. To gain practice-based insights into the reasons behind participants' interactional and communicative processes and participants' use of semiotic resources (WHY).
- 4. To gain practice-based insights into the impact of participants' interactional and communicative processes and of the use of semiotic resources on healthcare delivery (EFFECT).

Table 1 Frequently used terms and their working definition	
Term	Working definition
Participants	Patients, oncologists/haematologists, language-mediators
Communication problems	Lack of understanding/misunderstanding among participants in the medical consultation
Interactional processes	The ways in which participants in the medical consultation interact with each other by employing a wide range of semiotic resources (eg. using gestures to alert each other to misunderstandings)
Semiotic resources	Resources which participants in the medical consultation employ in order to co-construct meaning with each other and to relate to each other (eg. speech, gaze, body orientation, gestures)
Communicative processes	The ways in which participants in the medical consultation try to reach understanding (eg. seeking clarification, confirming understanding)

The definitions of terms used frequently in the goals of the study are found in table 1.

### **Outcomes**

- 1. To develop a set of evidence-based and ready-to-use recommendations for cancer patients and their families on communicating with their doctors through professional language mediators throughout the disease trajectory.
- 2. To develop a set of evidence-based recommendations on language-mediated communication with cancer patients for healthcare professionals and language mediators. These will be integrated into undergraduate and postgraduate programmes for medical students and interpreting students, as well as into courses designed for cultural mediators.

To display the interrelationships between the specific project activities and their intended outcomes, we provide an illustration of our outcome approach to logic model<sup>35</sup> (see figure 1).

### Method and analysis

### Design

This prospective, mixed-methods observational study allows for a novel and fine-grained analysis of communication between oncologists/haematologists and patients from an under-represented group in the literature, namely migrant patients with language barriers in oncology settings. We combine qualitative methodologies, such as multimodal interaction analysis<sup>36 37</sup> and qualitative content analysis,<sup>38</sup> with analysis using the Empathic Communication Coding System (ECCS)<sup>39-41</sup> in which a priori categories that are typically associated with quantitative methods are used. The above combination allows for

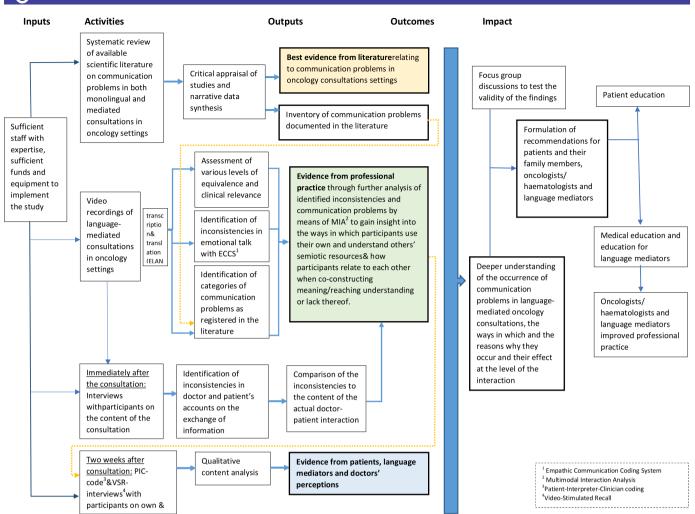


Figure 1 Logic model describing specific activities and intended outcomes.

a comprehensive and fine-grained analysis of authentic, naturally occurring doctor-patient interactions that go beyond the mere identification and description.

At the outset of the study, we will conduct a systematic literature review on communication problems in oncology consultations. Although we draw on the available evidence previous studies on language discordant and interpreter-mediated communication in healthcare settings have provided,<sup>24 42 43</sup> in this study we will narrow down the focus of the literature review to communication with cancer patients alone. The review will be conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.<sup>44</sup> Relevant publications will be searched in PubMed, Embase, Web of Science and Google Scholar (the search strategies can be found in online supplementary files 1–3). The evidence that will be gathered from the literature will inform the subsequent collection of evidence (eg. interviews with oncologists/haematologists and patients immediately after the interview) and through the analysis of video-recorded consultations and video-stimulated recall (VSR) interviews. The combination of evidence from the available literature, the professional practice and participants' perceptions

will allow us to gain a deeper understanding of the occurrence of communication problems in languagemediated consultations in oncology settings, as well as of the ways in which, and the reasons why, they occur and their effect at the level of interaction.

In order to test the face validity of our findings and to prepare the recommendations, we will organise two focus group discussions with stakeholder groups.

### Setting

The study will take place in three Belgian urban hospitals in Ghent and Antwerp that cater for a large number of migrant patients who do not speak the host language (Dutch) and language mediators are called to enable communication between them and the Dutch-speaking healthcare professionals.

### Sample

Considering this study to be primarily qualitative, we choose to rely on the concept of information power in order to appraise the sample size by relying on five items that determine sample size in qualitative studies, as proposed by Malterud *et al*<sup>45</sup>: study aim, sample

specificity, use of established theory, quality of dialogue and analysis strategy.

The scope of this study calls for a relatively large sample. We opt for purposeful sampling,<sup>46</sup> meaning that the participants and size of the sample will be determined by predefined criteria, such as language combination, confirmed language mediator bookings and availability of all participants in the consultation, that are relevant to the study objective. Moreover, the scarcity of theoretical perspectives on communication problems in languagemediated consultations in oncology settings requires a relatively large sample. To the best of our knowledge, there are no theoretical perspectives on communication problems in the literature available when it comes to cancer communication in interpreter-mediated consultations. Recent systematic reviews of the literature on communication in language-discordant oncology settings have shown that most of studies are observational and do not offer theoretical perspectives on communication problems.<sup>47</sup> An initial appraisal of the sample can be estimated at 30 video recorded consultations followed by 30 VSR-based interviews comprising 30 oncology patients, their oncologists/haematologists (approximately 20) and language mediators (approximately 10). The exact number of oncologists/haematologists and language mediators is subject to a number of factors, such as availability at the time of the scheduled consultation. The adequacy of the final sample size will be evaluated continuously during the research process and the appraisal of information power will be repeated along the process, supported by preliminary analvsis, as recommended by Malterud *et al.*<sup>45</sup> The data collection will start in 2020 and will end in 2021.

### Training prior to the data collection

We acknowledge that in qualitative studies, empirical data are co-constructed by complex interaction between the researcher and the study participants and that the researcher's experience, skills and personal qualities can shape the quality of interaction and thus the quality of data. The empirical data will be collected by a novice researcher (LV) who will receive training in the collection of primary data through interviews and video-recordings. The training will be provided by her supervisors (DK, PP), who have many years of experience in this research design. DK will train LV on the use of the ECCS<sup>48</sup> as adapted for interpretermediated consultations and on multimodal interaction analysis.<sup>36</sup>

### Eligibility criteria

### Inclusion criteria

- ► Turkish-speaking or Arabic-speaking migrant cancer patients ≥18 years and their family members who reside in Flanders, attend consultations in oncology settings, do not speak Dutch and, therefore, require language support.
- Dutch speaking oncologists/haematologists in oncology wards requiring language support when holding consultations with the above patients.

Professional language mediators with Dutch and Turkish/Arabic as working languages that are employed by the three hospitals as mentioned above in order to provide language support to the above patients and oncologists/haematologists.

### Recruitment

The recruitment of patients will occur consecutively (ie. each Turkish-speaking or Arabic-speaking patient scheduled to have a language-mediated consultation will be contacted). Access to the list of scheduled consultations will be granted by the Social Services department of each hospital and the participants' (patients, family members, oncologists/haematologists, language mediators) written informed consent will be sought as outlined in the informed consent forms approved by the ethics committees of the above hospitals. This method of recruitment has been successfully used in previous studies at the same hospitals by members of our team.<sup>48 49</sup>

### **Data collection**

Gathering evidence from the available literature: systematic review The review will focus on studies both in monolingual and language-mediated settings where communication is assessed at the level of the doctor-patient interaction and a value judgement has been assigned. The inclusion of monolingual consultations in the review will allow for the detection of communication problems in oncological consultations. The inclusion of mediated consultations will allow for the identification of communication problems that are inherent in language-mediated consultations.

The search strategy will be based on three concepts: oncology, communication problems, consultation/patientdoctor interaction. We opt to replace "language-mediator" with the terms "interpreter", "mediator" "language professional", "translator" in our concepts as these are widely used in the literature as umbrella terms. The inclusion and exclusion criteria are defined as follows: (1) publications report on primary data, (2) all research designs will be considered, (3) studies with a title and abstract in English will be included, (4) time restrictions do not apply, (5) studies that report on participants' own experiences with doctor-patient interaction in authentic consultations between adult cancer patients under treatment at various stages of the disease trajectory and their treating physicians will be included.

This review will allow us to register problems described in the literature to be experienced by patients and their families, doctors and language mediators during consultations in oncology. A typology of categories of communication problems will be generated on completion of the literature review and will be used for an additional screening of the video-recorded consultations.

## Gathering evidence from the professional practice: video recordings of language-mediated consultations

We will video record 10 mediated consultations in each of the above hospitals. In order to increase the likelihood of all categories of communication problems being captured as will have emerged from the systematic review of the literature, we will record consultations throughout the disease trajectory: at the beginning (eg. bad news delivery), during the disease trajectory (eg. shared decision-making on treatment) and at the end stage of disease (eg. discussing therapy failure and therapy discontinuation).

### Gathering evidence from the professional practice: semi-structured interviews with oncologists/haematologists and patients

Immediately after the consultation, we will hold semistructured interviews with the patients and the oncologists/haematologists. The interviews will allow us to gain insights into the doctors and patients' understanding of the topics that were addressed during the consultation. Gaining insights into the doctors and patients' understanding of the content of the consultation is particularly relevant when studying interpreter-mediated consultations. This is because the consultation as perceived by the participants is reflective of what is spoken by the interpreter, which may be subtly different from what was spoken by the clinician and the patient in the first place.<sup>50</sup> Registering participants' understanding of the content of the consultation immediately after the consultation will allow us to acquire a first overview of potential inconsistencies in the patients and doctors' understanding. These inconsistencies will be analysed further in greater detail at the subsequent levels of analysis.

### Gathering evidence from patients, language mediators and doctors' experience: VSR interviews

Two weeks after the consultation, we will measure participants' recall by relying on the Patient-Interpreter-Clinician coding (PICcode),<sup>50</sup> a comprehensive and rigorous methodology for measuring recall in interpreter-mediated oncology consultations. In the second part of the interview, we will play back extracts of the consultation that present communication problems. We will invite the oncologists/haematologists, patients and language mediators to comment in their own language on their own and the others' behaviour during individual semistructured VSR-interviews. The 2-week interval between the recording of the consultation and the VSR-interview will allow us to have the consultation transcribed in time, to have it translated and to have relevant excerpts selected which will be presented to the participants. The 2-week interval between the recording of the consultation and the VSR event is not unusual in the literature.49 51

### PATIENT AND PUBLIC INVOLVEMENT

This protocol was conceived without patient involvement. Patients were not invited to comment on the study design and were not consulted to develop patient relevant outcomes. Patients will be invited to interpret the results.

### ANALYSIS

The following analytical steps are presented in chronological order.

### First level of analysis: identification of inconsistencies in doctor-patient understanding of the content of the consultation (interviews after the consultation)

The research team will compare the patients and doctors' input on their understanding of the contents of the consultation as it will emerge from the interviews that will be held immediately after the consultation. Inconsistencies will be flagged and will be compared with the content of the actual doctor-patient interaction as shown in the video recording of the consultation.

### Second level of analysis: assessment of various levels of equivalence and clinical relevance (transcribed video recorded consultations)

Further inconsistencies between doctors, language mediators and patients' utterances as shown in the videorecorded consultations will be analysed by LV using ELAN, a professional tool for the creation of complex annotations on video and audio data (http://www.mpi. nl/corpus/html/elan/). The original utterances of the doctors and the patients as observed in the video recordings will be compared with the language mediators' renditions into the other language during the consultation. For the assessment of participants' utterances in the source language and the language mediators' renditions into the target language, Translation and Interpreting Studies scholars (LV, DK and colleagues) along with certified translators (based at KU Leuven) will perform an analysis by drawing on the concept of  $equivalence^{52}$  (1) at word and above wordlevel (lexical equivalence and collocations), (2) non-equivalence (the source language word expresses a concept which is unknown in the target language and culture), (3) at textual level (thematic, information structures and cohesion), (4) pragmatic equivalence and *implicature*<sup>53</sup> (what the speaker intended to communicate or what the speaker implied) and (5) semiotic equivalence (what semiotic resources mean for participants in a given culture). The assessment of the different levels of equivalence between source language utterances and their renditions into the target language will be reviewed against clinical relevance (PP, JW). Inconsistencies in terms of equivalence and clinical relevance will be flagged and analysed further by means of multimodal interaction analysis, in order to gain insights into the ways in which participants use their own and understand others' semiotic resources and how they relate to each other in interaction.

### Third level of analysis: identification of inconsistencies in emotional talk (transcribed video-recorded consultations)

Considering that cancer communication involves addressing patient emotion<sup>1 54–56</sup> and compromised emotional communication in language-mediated consultations might lead to suboptimal communication,<sup>41</sup> the

research team will identify different levels of emotional communication and will flag the language mediator's effect on the expression and management of emotions (by noticing shifts in the patients' emotion-laden statements and the doctors' levels of response to these). To this end, we will use the ECCS,<sup>39 40</sup> as adapted for language-mediated consultations,<sup>57</sup> in order to identify communication problems observed in the video recordings focusing on expression of, and response to, emotions.

The ECCS is a valid instrument for measuring empathic communication in monolingual physician-patient encounters and operationalises empathy as a transactional process. The tool focuses on behavioural aspects of empathic communication and divides patient-initiated empathic opportunities into statements of emotion, progress or challenge. The adapted version of the ECCS will allow us to identify different levels of emotional communication. An analysis of equivalence and clinical relevance similar to the second level of analysis that will also be applied to informative/instructional talk will be applied to emotional talk in order to identify any inconsistencies in the patients' emotion-laden statements, the languagemediators' renditions and the doctors' levels of response to the patients' emotional talk.

### Fourth level of analysis: multimodal analysis of instances in interaction where communication problems occur (transcribed video recorded consultations)

Considering that communication is a transactional process and patients, their family members attending the consultation, oncologists/haematologists and language mediators use a wide range of semiotic resources to this end, we will approach their interaction from the point of view of actions that carry communicative meaning<sup>58</sup> instead of taking only verbal interaction into account. Therefore, we will approach the coded instances of interaction where communication problems occur as outlined above by analysing the actual interaction in order to identify participants' interactional processes in relation to each other and the semiotic resources they draw on when trying to reach understanding. Studying the ways in which participants use semiotic resources, such as speech, gaze, body orientation and gestures, allows us to gain insights into the participants' culture as it becomes manifest through talk in interaction. Culture is a communicative phenomenon constituted through talk<sup>59</sup> and language carries meanings that are not in the same sense because language is associated with culture and culture is more extensive than language.<sup>60</sup>

The previously coded instances of emotional communication (ECCS), where shifts are being identified in the level or content of emotional expression will at this stage serve as units of analysis in which LV and DK will analyse the participants' verbal and non-verbal actions during the consultation. In order to do so, LV and DK will rely on existing analytical frameworks<sup>36 61</sup> especially tailored to mediated consultations, while scrutinising the role of the participants' gaze, body orientation, gesture and facial expressions. In this way, LV and DK will be able to investigate the ways in which gaze, body orientation, gestures and facial expressions are employed by participants as semiotic resources in interaction<sup>36 61–63</sup> (eg. complementing or contradicting the meaning of verbal interaction, used in parallel with, or separately from, verbal interaction or replacing the latter and so on). At the same time, the above analysis will allow us to observe the effect of all of the above agents' use of semiotic resources and interactional and communicative processes during which healthcare is being delivered.

For the analysis of the above semiotic resources, the units of analysis, namely instances of interaction previously coded for emotion and information exchange, will be transcribed. Time-based transcripts will be realised with ELAN that will enable us to create, edit, visualise and search annotations for video and audio data. This type of multimodal analysis<sup>36 37</sup> will allow us to gain further insights into the ways in which participants try to reach understanding in consultations on the cancer disease trajectory. In addition to that, it will allow us to observe the effect of participants' behaviour in interaction on the process of healthcare delivery.

### Fifth level of analysis: identification of categories of communication problems as registered in the literature

In order to capture a wider range of communication problems in the video-recorded consultations, the research team will screen them against the categories of communication problems that will emerge from the systematic literature review.

### Triangulation of data interpretation and preparation of dissemination of findings

Two focus group discussions for each stakeholders group (patients and family members, oncologists/haematologists and language mediators) will be conducted in the participants' languages (5-10 participants per group) in order to test the validity of our findings and formulate a set of recommendations for patients, family members and integrate them in medical and interpreter education and training modules for cultural mediators. The focus groups will be facilitated by LV and at least one other member of the research team with experience in focus groups. The discussions will be audio-recorded and one of the facilitators will be taking extensive notes. Every effort will be made to ensure gender balance. The first 10 min will consist of introductions and a brief overview of the background and purposes of the focus group. Participants will be granted access to the draft recommendations and will be asked to share their reflections on them and identify any items that might be ambiguous, confusing or difficult to understand and/or to implement. Participants' body language, posture and voice tone will be documented in the observation notes and will be reviewed during the analysis of the data.<sup>64</sup>

### ETHICS AND DISSEMINATION

The study has been approved by three independent ethics committees at the respective hospitals (Belgian registration number: B670201940349). There are no risks associated with this study. Participants' written informed consent will be sought prior to their inclusion in the study. Participants' anonymity and privacy will be duly protected.

The findings of the study will be communicated using a comprehensive dissemination strategy aimed (1) at patients and their family members (eg. brochure to be made available on the website of Stand Up To Cancer, the Flemish Cancer Society and to be distributed to patient groups and patient organisations), (2) educators (eg. integration of findings in medical- and interpreter education and cultural mediator training), (3) clinicians (eg. presentation of findings at oncology wards in Flanders, making findings available to the Belgian Society of Medical Oncology), (4) language mediators (eg. making findings available to the Belgian Chamber of Translators and Interpreters, to the Training and Certification Unit for Public Service Interpreting and Translation at the Flanders Integration Agency; to the Federal Public Service for Health, Food Chain Safety and Environment that distributes language/cultural mediators to the Belgian hospitals), (5) policy makers (eg. making findings available to hospital boards). At the same time, the results of the study will be published in national and international, peer-reviewed journals and presented at international conferences.

### LIMITATIONS

Despite the complementary methodologies that will be used and the fine-grained analysis that will be applied to primary data, we do acknowledge that this study will provide only limited insights into the complexity of communication problems in language-mediated consultations with migrant oncology patients. In addition, generalisability of findings to other languages and contexts should be carefully considered.

**Contributors** DK and PP conceived of the study. DK wrote three quarters of the study protocol. LV wrote the introduction. JW, ID, PP and LV provided critical feedback during the conception of the study and the writing up of the protocol.

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