

# Prologue



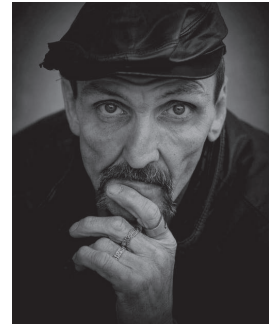
## WHY WE STARTED THIS RESEARCH



Mrs. A., an 83-year-old female diagnosed with a cT1bN0M0 carcinoma of the vocal cords. She is widowed and lives in a service flat together with her cat. She loves to sing in a choir together with her friends. During the last years she started to use a rollator due to mobility problems, and she has showed early signs of dementia. She smokes a package of cigarettes each

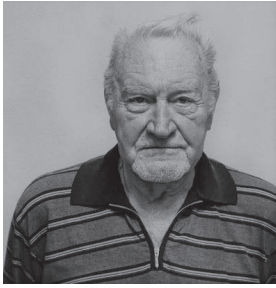
day. Mrs. A. wishes to continue singing in her choir, and she is concerned that treatment of the tumor will withhold her from doing that. She wants her doctor to choose the best treatment for her, as she says “he’s the expert”.

Mr. B., a 64-year-old male with a large carcinoma of the oral cavity with metastasis to the lymph nodes of the right neck (cT4aN2bM0). He works as a dock worker in the international port of Rotterdam. Mr. B. smokes hand rolled tobacco since the age of 13, and developed alcohol abuse since his wife left him. Every day he drinks 7 half liter cans of beer. He also suffers from type 2 diabetes and had a minor stroke last year. He is proud to avoid doctors’ visits as much as possible since he doesn’t like other people interfering with his life or pointing out the consequences of his lifestyle. He therefore doesn’t want to know anything about survival chances, “let those doctors do their jobs, I’ll do mine”.



Mrs. C., a 48-year-old female with an HPV (Human Papilloma Virus) related oropharyngeal tumor with metastasis to the neck (cT2N2M0). She has a husband and two kids, boy and girl, aged 16 and 19. She works as an accountant and loves swimming. Mrs. C. consequently seeks to maintain a healthy lifestyle: she has never smoked and rarely drinks alcohol. Besides some issues with hay fever and eczema, she has no other comorbidities. Mrs. C. is anxious about her diagnosis and feels insecure about all that is about to happen. She wants to be informed in detail about her chances of complete cure and the side-effects

of the treatment, in order to make a well-considered treatment decision.



Mr. D., a 72-year-old male with a recurrent rT2N1M1 hypopharyngeal carcinoma with metastasis to the lungs. He used to work as a butcher and ran his own store together with his wife for over 40 years. He and his wife have already gone through a lot during the treatment of his primary tumor, including a feeding tube, severe dyspnea and multiple admissions to the hospital. They wish to enjoy each other's company for as long as possible and Mr. D. places equal

importance to quality and quantity of life. He wants to be informed about how his life will look like in the forthcoming months.

Despite their differences, all patients do have the same kind of questions at some point of time during their disease trajectory:

*“What are my chances to survive?”*

*“If I am to proceed with the major surgery or radiotherapy the doctor proposes, what will be the consequences for the quality of my life?”*

*“Could I imagine living without being able to talk or swallow?”*

*“What does my diagnosis and upcoming treatment imply for my family and loved ones?”*

*“How can I best make clear to my doctor what's important to me in life?”*

*“Do I actually have a choice?”*