



Patient journey insights: The Netherlands

Introduction

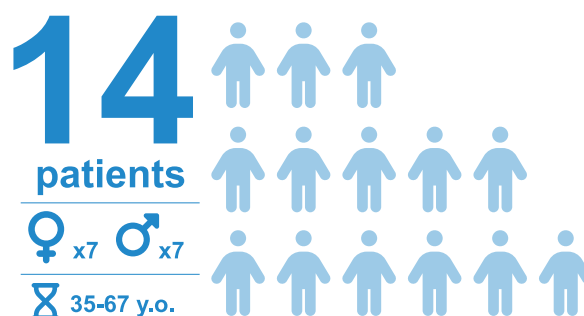
The patient on the receiving end of the diagnosis lives in a world completely different from the clinical and precise environment of a pathology lab. To shed some light on how this person may experience their diagnostic journey, we conducted a study that investigated the insights of **14 patients** from the Netherlands at different stages of obtaining their diagnoses.

Scope / sample size / technicalities

The sample of patients consisted of 7 men and 7 women, aged between 35-67 and based in the Netherlands. All patients entered the diagnostic process and had a biopsy or blood test for cancer research no longer than 3 months before the interview.

This sample encompasses patients with the following characteristics:

- Those who had received a negative result (no cancer), a positive result (cancer) and patients who were still waiting for test results
- Different types of cancer (skin cancer, breast cancer, ovarian cancer, prostate cancer, leukaemia, lung cancer)
- Entered the journey through population screening or because of self-observed symptoms followed by a GP visit



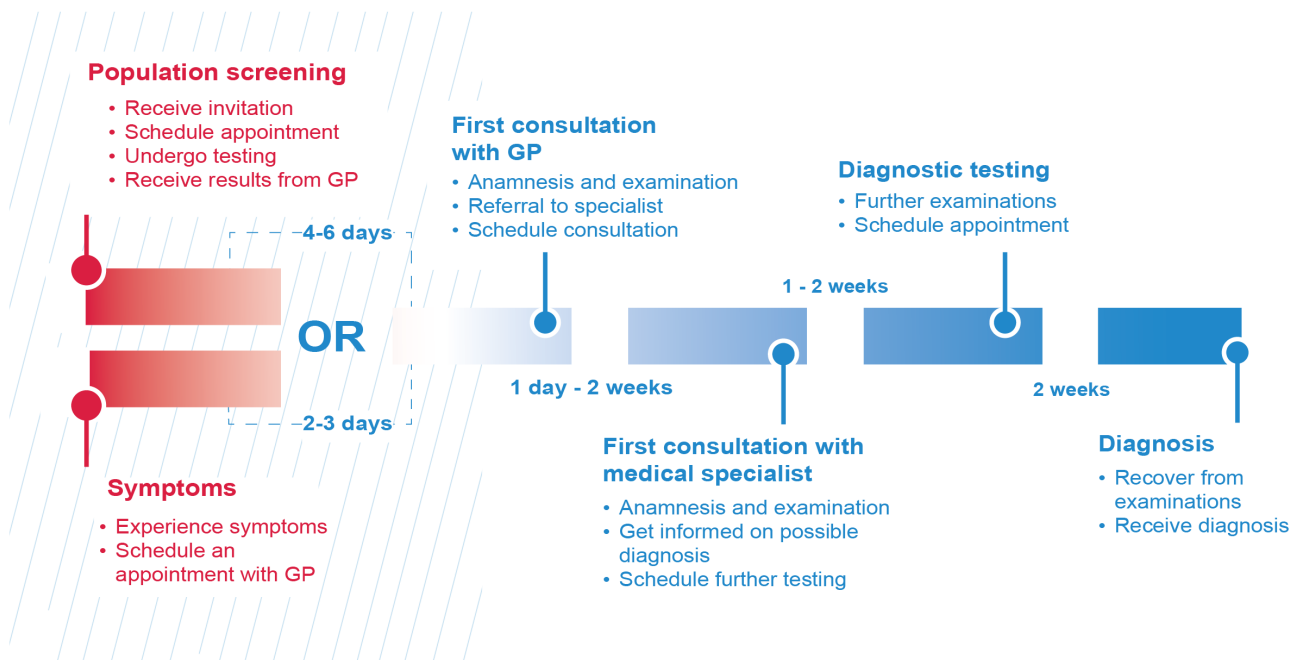


Figure 1: Estimated timeline from first complaints to diagnosis

Main findings

1. Waiting time makes up a significant portion of the process leading up to a diagnosis

Over the course of the survey, it became clear that it is common for the total patient journey up until receiving a diagnosis to take up to **6.6 weeks**, of which 2 weeks tend to represent the waiting time due to histology. The biggest part of the patient journey until diagnosis in the Netherlands can be seen as waiting time for the patient.

Waiting time occurs when patients do not perform any actions or attend appointments. This can follow every time the patient is referred to a different HCP, and when histological examinations are performed on a biopsy (or blood sample). In the current research sample, this waiting time takes up to **a third to half of the total duration** of the patient journey.

2. All patients experience the journey up to a diagnosis as stressful or unpleasant

When entering the patient journey, patients in this research usually feel resigned. When the HCP first expresses their worry about the possibility of cancer, patients begin to experience heightened anxiety, fear and stress. These unpleasant emotions remain whilst the patient is going through further examinations and awaits a diagnosis.

When asked, patients indicate that it is primarily the uncertainty that makes the waiting time unpleasant for them. Regardless of the outcome (positive or negative), most patients feel relieved when they have clarity about their diagnosis. This supports the idea that the feeling of uncertainty while waiting has a significant impact on the patient experience.

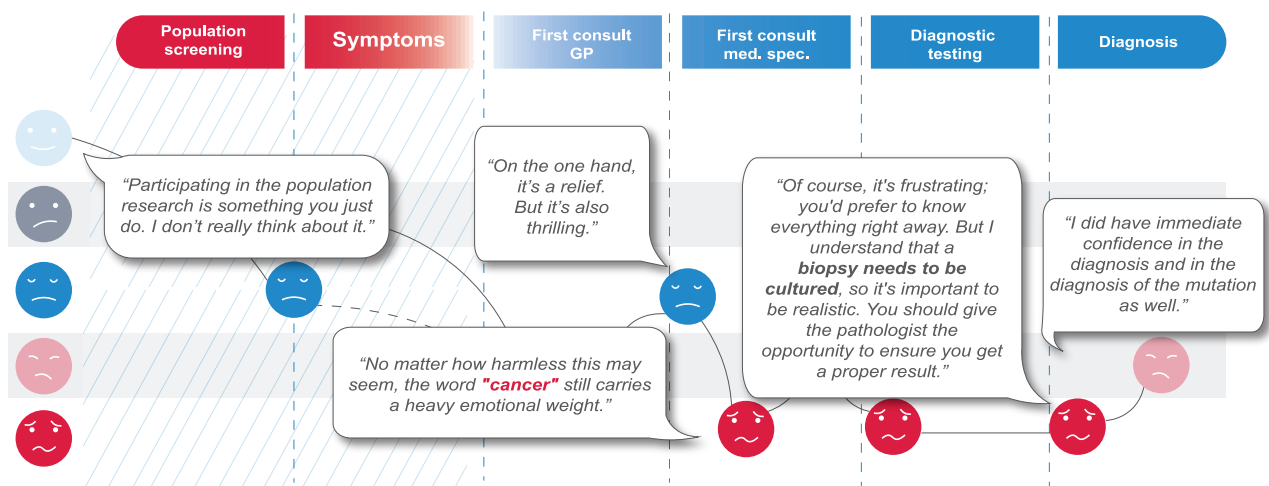


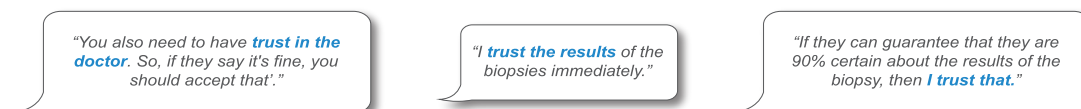
Figure 2: Tracked emotional experience throughout the different stages of the patient journey

3. Patients have a limited understanding of the diagnostic process, but still place their trust in the procedure and the outcome

Almost all surveyed patients held incorrect assumptions about the diagnostic procedure, specifically about what happens to the tissue that is being examined. The patients believe that the diagnosis takes longer to produce because the tissue needs to be cultured before it can be studied. Some patients also associated the reception of a favourable “no cancer” result with longer waiting times, believing that the diagnosis confirming cancer takes less time to make.

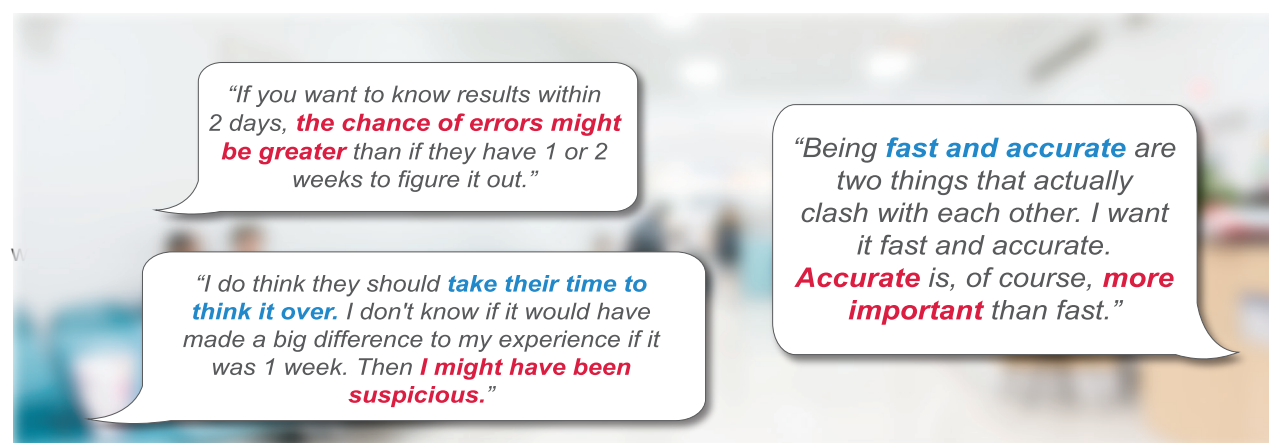


Notably, none of the patients questioned the procedure and whether the examination was done correctly. The representatives in this sample largely had no difficulty with completely trusting their HCPs and needed no extra technical information on the process. Naturally, there are exceptions: one patient noted conflicting interpretations by two specialists and expressed the need to consult an independent expert, like a pathologist.



4. Waiting time causes negative emotions, but is seen as necessary for an accurate diagnosis

Despite experiencing strong negative emotions throughout the patient journey, all patients see the waiting time as unavoidable, connecting longer diagnostic time to higher accuracy. Even though all patients preferred to have the waiting time be as short as possible, they also linked it to the accuracy of the diagnosis and expressed unwillingness to speed up the process if it came at the expense of accuracy. This conviction likely stems from the belief that tissue needs to be cultured before the examination.



Nevertheless, many patients in this research expressed that if they could change anything in the process up to diagnosis, it would be reducing the waiting time. They stated that every day of waiting to receive a diagnosis is one too many and they don't like being in the unknown. Patients described waiting time between examinations and diagnosis as a period that had a significant impact on them.



5. Patients base their expectations on the interactions with their HCPs

When faced with an HCP who expressed more concern and a higher sense of urgency, patients tended to assume that waiting time was related to the urgency of their case.

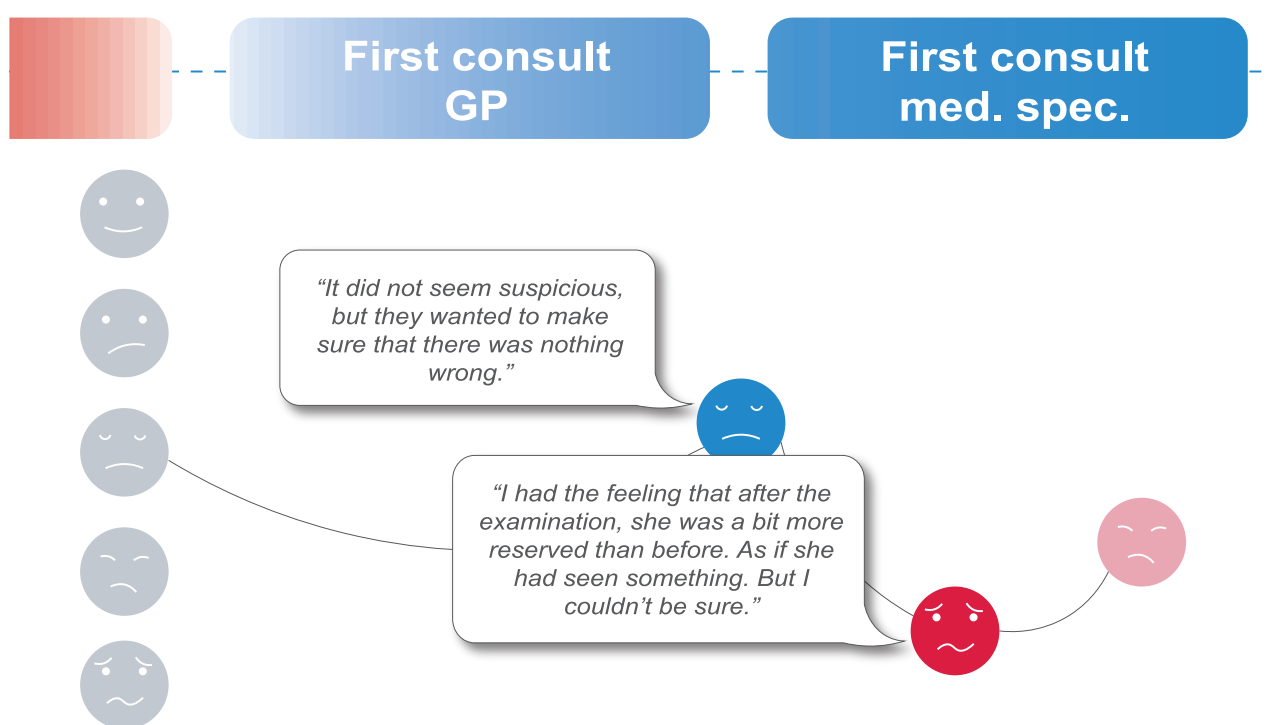
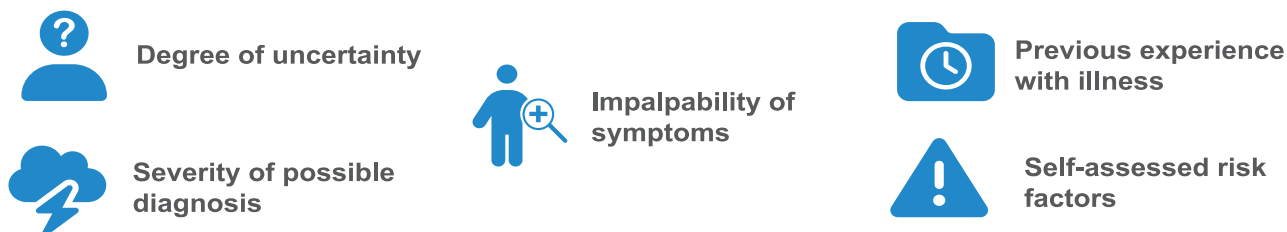


Figure 3: The impact of the interaction with the HCP on the patient's perception of the journey

When the process feels hurried by the HCP and they strive for little waiting time between appointments, the patient may see this as a red flag. On the other hand, if HCPs do not try to speed up the process, patients see this as a sign that there is probably not much to worry about. Overall, patients tend to be sensitive to the “signals” sent by the HCPs.

Differences in personality and circumstances drive the responsiveness of the patient to their patient journey.

Over the course of the survey, five factors influencing the responses of patients were determined:



Conclusion

As the study shows, obtaining a diagnosis becomes a big part of a patient's life, regardless of the outcome. While patients put a lot of trust in the expertise of the pathology professionals, their lack of understanding of the diagnostic process and personal circumstances or specificities of their personalities can significantly influence how the patients experience their journey towards a diagnosis. Many factors shape the diagnostic journey of a patient, and the emotional impact of a prolonged waiting time cannot be understated.

