

Appendices

A: Interview guide

Introduction Good morning/afternoon, thank you for participating in this interview. My name is Maurits, and I am conducting a study on the experiences of patient advocates within oncology patient organizations in the Netherlands. We aim to understand the nature of this role, your motivational drivers, the challenges you experience, and how your contributions are recognized and compensated. Your participation is entirely voluntary and confidential. Everything you share will be anonymized.

1. Role, Responsibilities, and Demands

Let's begin by discussing your role as a patient advocate. We are interested in how you entered this role and what your responsibilities entail.

- Are you a patient, a former patient, a relative, or involved in another capacity?
- How did you become involved in patient advocacy?
- Which patient organization are you affiliated with?
- What are your core responsibilities as a patient advocate?
- How many hours per week do you dedicate to your advocacy role?
- Can you provide an example of a recent project or activity you contributed to?
- What do you perceive as the greatest challenges in this role?
- What kind of pressures do you experience in your role?
- Have there been moments where the work felt overwhelming? If so, could you describe such a situation?

2. Energy Resources and Motivations

We have discussed the demands of your role; now, let's explore what provides you with energy and satisfaction.

- How would you describe the tasks you perform for the organization?
- How much autonomy do you experience in fulfilling your role? For example, can you choose tasks that align with your personal interests?
- What forms of support or professional guidance do you receive?
- How do you experience collaboration with healthcare professionals, researchers, policymakers, or other patient organizations?
- In what ways do you receive appreciation for your efforts? How is this expressed?
- What do you personally gain from this work (e.g., sense of purpose, new knowledge, social connections, feeling of contribution)?

3. Impact and Meaning

Having discussed what drives you, I would like to explore how you perceive your impact.

- What impact do you think patient advocates have in the current healthcare landscape?
- Can you describe a moment where you felt your contribution truly made a difference?
- How did that make you feel? Did you feel heard, recognized, and significant?
- In what ways has your involvement affected policy, clinical care, or research?
- How does your work as a patient advocate influence your personal life?

4. Motivation and Sustainability

Building on the impact of your work, we would like to learn more about the motivations that keep you engaged.

- What motivates you to continue this work? Can you describe a situation where you felt particularly motivated?
- Have there been moments where you doubted your commitment or considered stopping? What were the underlying factors?
- What helps you stay motivated? Conversely, what could lead to a loss of motivation?

5. Appreciation and Compensation (Material and Non-material)

We have discussed your intrinsic motivations. Now, let's discuss how you experience the recognition for your efforts, including financial and non-financial compensation (e.g., conference attendance, co-authorship).

- What forms of appreciation are important to you?
- Have you ever received compensation for your advocacy work? If so, what form did it take, and how did you perceive it?
- If not, what is your view on this?
- Have you ever requested compensation? Why or why not?
- What would be a fair or appropriate form of recognition in your view?
- How might structural financial compensation influence the time and energy you dedicate to this work?
- Do you believe your contributions to projects should be compensated? Why or why not?
- How clear or transparent is the policy regarding compensation within your organization?
- If a budget were available, would you prefer financial compensation or other forms of rewards (e.g., training, coaching, travel expenses, co-authorship)? Why?

6. Reflection and Conclusion

- On a scale of 0 to 10, how satisfied are you with your work as a patient advocate?
- On a scale of 0 to 10, how likely is it that you will still be active as a patient advocate in one year's time?
- What should change to better support your role?
- How did you experience this interview? Did this conversation change how you view your role?
- Is there anything else you would like to share that we haven't discussed yet?

Thank you for your time and insights. If you have any additional thoughts after this conversation, please feel free to email me.