

## Additional file 5: Demographic survey – Focus groups

**For the paper Lalova-Spinks et al., “*What patients value in data reuse for oncology research: a multi-stakeholder qualitative study to inform the European Health Data Space implementation in Belgium and beyond*”, Archives of Public Health (2026), doi: 10.1186/s13690-026-01884-5**

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### Start of Block: Default Question Block

Dear participants,

Thank you for joining our discussion groups on patient value and health data (re)use in oncology research!

With this survey, we would like to ask you several questions that would allow us to better prepare the discussion. The survey and the discussion group you will participate in are part of a study within the Symphony of Us – a project on patient value in oncology research, initiated and financed by the King Baudouin Foundation. Symphony of Us is a collaboration between AP Hogeschool Antwerpen, Ghent University and Université libre de Bruxelles.

It will take you approximately **5 minutes** to complete the survey.

We look forward to meeting you soon!

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**Q2 What is your name and surname?**

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**Q3 What characterizes you best?**

- ☐ Patient (you have or had cancer in the past) (1)
  - ☐ Patient representative (e.g., a member of a patient organization, patient expert, patient advocate...) (2)
  - ☐ I am both a patient and a patient representative (3)
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Display this question:

*If What characterizes you best? = Patient (you have or had cancer in the past)*

*Or What characterizes you best? = I am both a patient and a patient representative*

**Q4 Please indicate whether you are in remission or still in treatment.**

☐ In remission (1)

☐ In treatment (2)

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**Q8 Please specify the type of cancer you had and/or the type of cancer you are working in as a patient representative.**

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**Q9 Which country do you currently reside in?**

☐ Belgium (1)

☐ Other, please specify (2) \_\_\_\_\_

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**Q10 What is your gender?**

☐ Male (1)

☐ Female (2)

☐ Non-binary / other (3)

☐ Prefer not to say (4)

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**Q11 What is your age group?**

- ☐ 18-24 (1)
  - ☐ 25-34 (2)
  - ☐ 35-44 (3)
  - ☐ 45-54 (4)
  - ☐ 55-64 (5)
  - ☐ 65-74 (6)
  - ☐ 75 or older (7)
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**Q12 What is the highest level of education that you have completed?**

- ☐ Primary education (primary school) (1)
  - ☐ Secondary education (secondary school) (2)
  - ☐ Bachelor's degree or equivalent (3)
  - ☐ Master's degree or equivalent (4)
  - ☐ Doctorate degree (5)
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Q13

**Have you ever participated in a clinical trial or another type of biomedical study before?**

*A **clinical trial** is a bio-medical study in which participants are assigned to receive an experimental treatment in order to investigate its effects on health outcomes, usually compared to another (or sometimes no) treatment.*

- ☐ Yes (1)
- ☐ No (2)
- ☐ I do not know (3)
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Q14

**Have you ever allowed your personal data, collected when receiving healthcare, to be re-used for biomedical research purposes?**

***Personal data** is any information that is related to you, such as your name, gender, age, as well as information about your health (disease, blood test results...) or your genetic data.*

- ☐ Yes (1)
- ☐ No (2)
- ☐ I do not know (3)
- 

**Q15 Have you followed any courses targeted towards patients on the topics of medicines development, clinical or biomedical research, or patient engagement?**

- ☐ Yes (1)
- ☐ No (2)
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Q16

**Have you ever collaborated with researchers or other stakeholders in decisions whether or how health data from patients other than you should be re-used for research? For instance, advising about questions such as for what type of research studies the data should be**

*used, or with what type of stakeholders the data should be shared (academics, commercial, etc).*

☐ Yes (1)

☐ No (2)

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**Q17 Have you ever heard about the EU General Data Protection Regulation (GDPR)?**

☐ Yes (1)

☐ No (2)

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*Display this question:*

*If Have you ever heard about the EU General Data Protection Regulation (GDPR)? = Yes*

**Q18 What is your main source of information about the GDPR?** *(multiple answers possible)*

- ☐ The news (1)
  - ☐ My employer (2)
  - ☐ Educational authorities (school, university) (3)
  - ☐ My friends and family (4)
  - ☐ Social media (5)
  - ☐ Email from companies that use my personal information (e.g., email from my bank) (6)
  - ☐ A healthcare provider (e.g., a hospital) (7)
  - ☐ Through my experience as a participant in biomedical research (e.g. during the informed consent process) (8)
  - ☐ I have gotten specialized training in data protection (9)
  - ☐ Other, please specify (10)
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**Q19 Have you ever heard about the European Health Data Space Regulation?**

- ☐ Yes (1)
- ☐ No (2)

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*Display this question:*

*If Have you ever heard about the European Health Data Space Regulation? = Yes*

**Q20 What is your main source of information about the European Health Data Space?**  
(multiple answers possible)

- ☐ The news (1)
  - ☐ My employer (2)
  - ☐ Social media (3)
  - ☐ My friends and family (4)
  - ☐ Patient organizations (5)
  - ☐ Other, please specify (6)
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**Q21 Would you like to share any additional comments before we meet at our discussion group?**

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End of Block: Default Question Block

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