Additional file 2: GRIPP 2 Checklist

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

Section and topic	Item	Reported on page No
1: Aim	Patients were involved to contribute to all phases of the study (study design, data collection and analysis), with the aim to ensure that the study incorporates the patient perspective and is relevant to patients. Patients are mentioned throughout the paper by using the term '*patient-researchers'*. Collaboration with the patient-researchers is structurally embedded in the broader project "Symphony of Us", of which this study is a part.	**7**
2: Methods	Related to the study design, patient researchers were invited to practically elaborate the sequential qualitative design, i.e. to provide feedback on the interview and focus group questionnaires, and on materials that were presented to patients participating in the study (namely, the introductory presentation for the focus groups). Related to the data collection, patient-researchers were invited to participate (as observers or co-leaders) or lead the interviews and focus groups upon availability. The patient-researchers were offered the opportunity for a preparatory meeting with the researcher leading this study (TLS) before their participation in an interview or focus group. They were	**7-8**

Section and topic	Item	Reported on page No
	also invited to debrief (either via a call, or via emails) after each interview/focus group. Related to the data analysis, patient-researchers were invited to pilot code the transcripts resulting from the study, and to participate in discussions (online or in person), e.g. on alignment about the pilot coding, or on interpretation of the results.	
3: Study results	A total number of four patient researchers were involved voluntarily throughout the study based on availability (IVZ, WD, BC, LB). One of the patient-researchers has an academic background and previous experience in the topic (IVZ). Related to the study design, all four patient researchers provided written and/or oral feedback on the questionnaires and other materials used. Patient-researchers suggested rephrasing, deleting or adding questions. Related to data collection, all four patient-researchers at least participated in one or more of the interviews and three at least participated in one of the focus groups (out of which two focus groups were completely led by a patient-researcher). The majority preferred an observer role, and had the opportunity to get involved in the discussions when they felt comfortable to do so. One focus group did not have a patient-researcher involved as it was conducted in French (all patient-researchers are native Dutch speakers).	**N.A.**

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	Related to the data analysis, one patient-researcher was involved in the pilot coding process and all patient-researchers contributed to discussions on the study results. Most patient-researchers expressed discomfort with leading the interviews/focus groups due to limited technical knowledge on the topic of the study, but reported that participation was rewarding and educational. The debriefings after each data collection activity allowed them to share reflections and identify key learnings, which enriched the interpretation of results. The involvement was positive, though voluntary participation meant that not all were able or willing to engage at every stage of the study.	
4: Discussion and conclusions	The involvement of patient-researchers had a clear and substantive influence on the study. They helped improve the design of interview guides and focus group materials, ensuring relevance to both experienced and less experienced patients. Their comments during debriefings and data analysis discussions sharpened the interpretation of findings and provided insights that academic researchers might have overlooked. Having both patients with and without academic backgrounds enriched the process, balancing lived experience with more technical contributions (e.g., in pilot coding, in the facilitation of focus groups). A challenge was the voluntary nature of the role, which limited sustained engagement for some participants and required flexibility from the team. Despite this, involvement enhanced the study's credibility, relevance, and interpretative depth.	**N.A.**

Section and topic	Item	Reported on page No
5: Reflections/critical perspective	Overall, the collaboration worked well, especially due to the prior structured onboarding in the broader project. The opportunity offered for preparatory meetings and debriefings within this specific study created a safe space for learning and reflection. Patient-researchers reported positive experiences, trust, and having felt supported in the process. The structured training in qualitative methods offered at the project start (within the broader "Symphony of Us" initiative) proved valuable. At the same time, limitations were observed: not all patient-researchers felt confident leading the discussions, and availability varied. In future studies, it would be valuable to consider offering complementary topic-specific training to interested patients. However, it is equally important to maintain the balance between representation of lived experience and specialized knowledge on the topic. Combining input from patients with and without prior expertise on the topic enriched both the design and outcomes.	**N.A.**