WAYFIND-R: A global, real-world precision oncology registry-socioeconomic features





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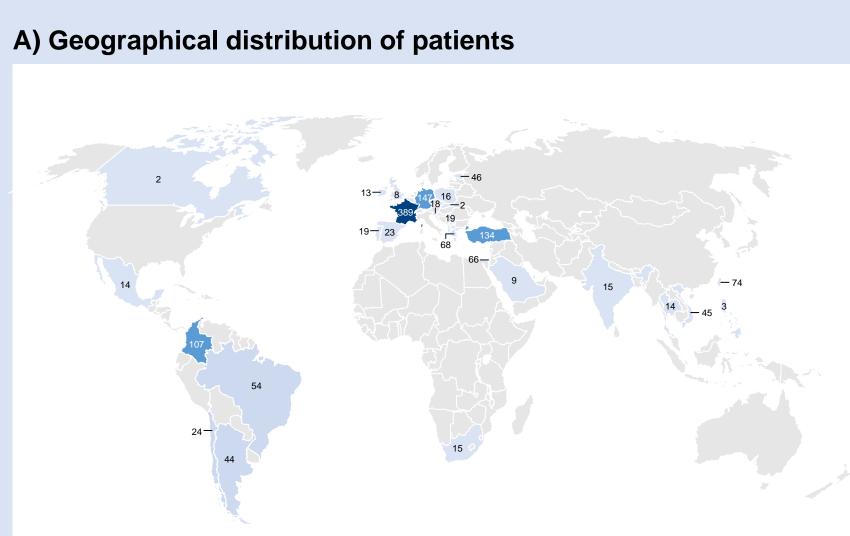
• WAYFIND-R (NCT04529122), a global, prospective pan-cancer precision oncology registry of patients diagnosed with a malignant solid tumour profiled with next-generation sequencing (NGS) collects long-term, high-quality, real-world data on those patients' characteristics and outcomes, as well as socioeconomic factors. It aims to be a fit-for-purpose data source for researchers internationally.¹

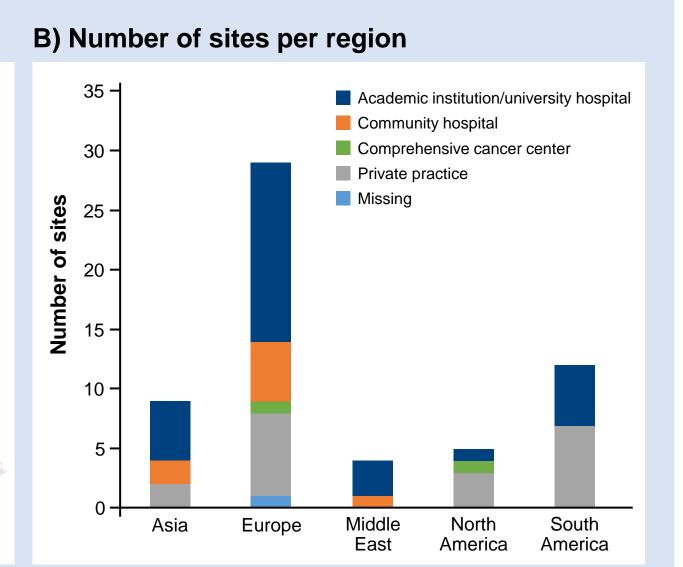


 Patient data are collected longitudinally and standardised into a centralised database. These include tumour characteristics, comorbidities, biomarker data, NGS test results, NGS test characteristics, molecular tumour board decisions, cancer treatments, and outcomes (Supplemental Figure 1A). Here, we describe sociodemographic and socioeconomic characteristics of WAYFIND-R patients.



Figure 1. Distribution of patients and site characteristics





South

Table 1. Sociodemographic data per region

	(n = 1,388)	(n = 15)	(n = 151)	(n = 768)	(n = 209)	America (n = 16)	America (n = 229)
Median age at diagnosis, years (range)	62 (15–91)	61 (35–73)	59 (27–86)	64 (17–91)	60 (27–82)	55 (23–81)	59 (15–87)
Race							
Asian	155 (11.2)	2 (13.3)	151 (100)	1 (< 1)	0	0	1 (< 1)
Black	4 (< 1)	1 (6.7)	0	1 (< 1)	0	0	2 (< 1)
White	711 (51.2)	11 (73.3)	0	364 (47.0)	208 (99.5)	15 (93.8)	113 (49.3)
Mixed/other	101 (7.3)	1 (6.7)	0	1 (< 1)	0	0	99 (43.2)
Not reported*	415 (29.9)	0	0	399 (52.0)	1 (< 1)	1 (6.3)	14 (6.1)
Missing	2 (< 1)	0	0	2 (< 1)	0	0	0
Sex							
Female	693 (49.9)	9 (60.0)	54 (35.8)	399 (52.0)	100 (47.9)	9 (56.3)	122 (53.3)
Smoking status							
Never	569 (41.0)	8 (53.3)	91 (60.3)	254 (33.1)	82 (39.2)	9 (56.3)	125 (54.6)
Current smoker	182 (13.1)	6 (40.0)	8 (5.3)	123 (16.1)	27 (12.9)	2 (12.5)	16 (7.0)
Former smoker	491 (35.4)	1 (6.7)	49 (32.5)	277 (36.1)	79 (37.8)	5 (31.3)	80 (34.9)
Not reported	135 (9.7)	0	1 (< 1)	112 (14.6)	14 (6.7)	0	8 (3.5)
Missing	8 (< 1)	0	2 (1.3)	2 (< 1)	7 (3.3)	0	0
Highest level of education							
No formal/early childhood education	4 (< 1)	0	0	4 (< 1)	0	0	0
Primary education	124 (8.9)	0	14 (9.3)	45 (5.9)	37 (17.7)	2 (12.5)	26 (11.4)
Secondary education	462 (33.3)	2 (13.3)	59 (39.1)	286 (37.2)	58 (27.8)	0	57 (24.9)
Post-secondary, non-tertiary education	155 (11.2)	2 (13.3)	27 (17.9)	78 (10.2)	19 (9.1)	6 (37.5)	23 (10.0)
Tertiary education	366 (26.4)	11 (73.3)	40 (26.5)	148 (19.3)	63 (30.1)	8 (50.0)	96 (41.9)
Not reported	267 (19.2)	0	8 (5.3)	201 (26.2)	31 (14.8)	0	27 (11.8)
Missing	10 (< 1)	0	3 (2.0)	6 (< 1)	1 (< 1)	0	0
Employment status							
Not employed/student/homemaker	174 (12.5)	1 (6.7)	22 (14.6)	51 (6.6)	56 (26.8)	5 (31.3)	39 (17.0)
Part time/self-employed/full time	480 (34.6)	8 (53.4)	60 (33.8)	253 (32.9)	51 (24.4)	8 (50.1)	100 (43.7)
Retired	579 (41.7)	6 (40.0)	63 (41.7)	360 (46.9)	85 (40.7)	3 (18.8)	62 (27.1)
Not reported	147 (10.6)	0	3 (2.0)	100 (13.0)	16 (7.7)	0	28 (12.2)
Missing	8 (< 1)	0	3 (2.0)	4 (< 1)	1 (< 1)	0	0
Insurance							
No insurance	61 (4.4)	1 (6.7)	8 (5.3)	9 (1.2)	31 (14.8)	5 (31.3)	7 (3.1)
Private/employer-provided insurance	367 (26.4)	14 (93.3)	32 (21.2)	118 (15.4)	45 (21.5)	6 (37.5)	152 (66.4)
Government insurance	843 (60.7)	0	107 (70.9)	585 (76.2)	105 (50.2)	5 (31.3)	41 (17.9)
Not reported/prefer not to say	109 (7.9)	0	1 (< 1)	52 (6.8)	27 (12.9)	0	29 (12.7)
Missing	8 (< 1)	0	3 (2.0)	4 (< 1)	1 (< 1)	0	0

Data are n (%) and refer to enrolment/baseline unless otherwise stated. *Not routinely collected in some sites.

- Of the 2,115 patients enrolled by 31 July 2023 from 75 sites across 28 countries globally (Figure 1), 1,388 patients had complete baseline data and cancer-related details available for analysis (Supplemental Figure 1B).
- The median age at diagnosis was 62 years (range: 15–91), 50% were female and 51% were White (Table 1 and Supplemental Table 1). Race/ethnicity was available for 971 patients (White: 73%; Asian: 16%; mixed or other [mostly Hispanic]: 10.4%; Black: < 1%). Out-of-pocket payment varied across regions (Europe: < 10%; South America: < 10%; Middle East: 21%; Asia: 51%), as did educational level (tertiary education: 24%, 53%, 38% and 39%, respectively) and government insurance (84%, 19%, 55% and 79%, respectively). Sociodemographic data categorised by region are shown in **Table 1**.
- Overall, 141 cancer types were included and 82% of patients had metastatic disease when enrolled. The most common cancer types were lung (29%; n = 400), colon (11%; n = 147), pancreas (9%; n = 118), breast (7%; n = 102) and ovary (5%; n = 64).
- Approximately 64% of all patients had their treatment reimbursed either by insurance or national health service (Table 2).
- NGS turnaround time from test request to receipt of results, had a median duration of 13 and 21 days for commercial and locally developed tests, respectively (Table 3).
- Figure 2 shows how physicians and academic researchers can access and analyse anonymised data from WAYFIND-R.

Table 2. Means of	access to	treatment I	by cancer	type
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	All patients (n = 1,388)	Breast (n = 102)	Colon (n = 147)	Lung (n = 400)	Ovary (n = 64)	Pancreas (n = 118)	All other cancers (n = 559)
Early access programme	0.8	1.2	0.8	0	0	0	2.1
Individual patient funding*	2.7	0	2.4	2.5	3.6	4.7	4.2
Other (National Health Services, state-funded)	13.6	15.7	23.4	17.2	10.9	8.4	17.1
Private payment [†]	9.6	8.4	8.1	18.1	5.5	11.2	9.7
Reimbursement [‡]	50.6	67.5	57.3	59.1	74.6	72.0	61.1
Missing	22.7	7.2	8.1	3.1	5.5	3.7	5.8

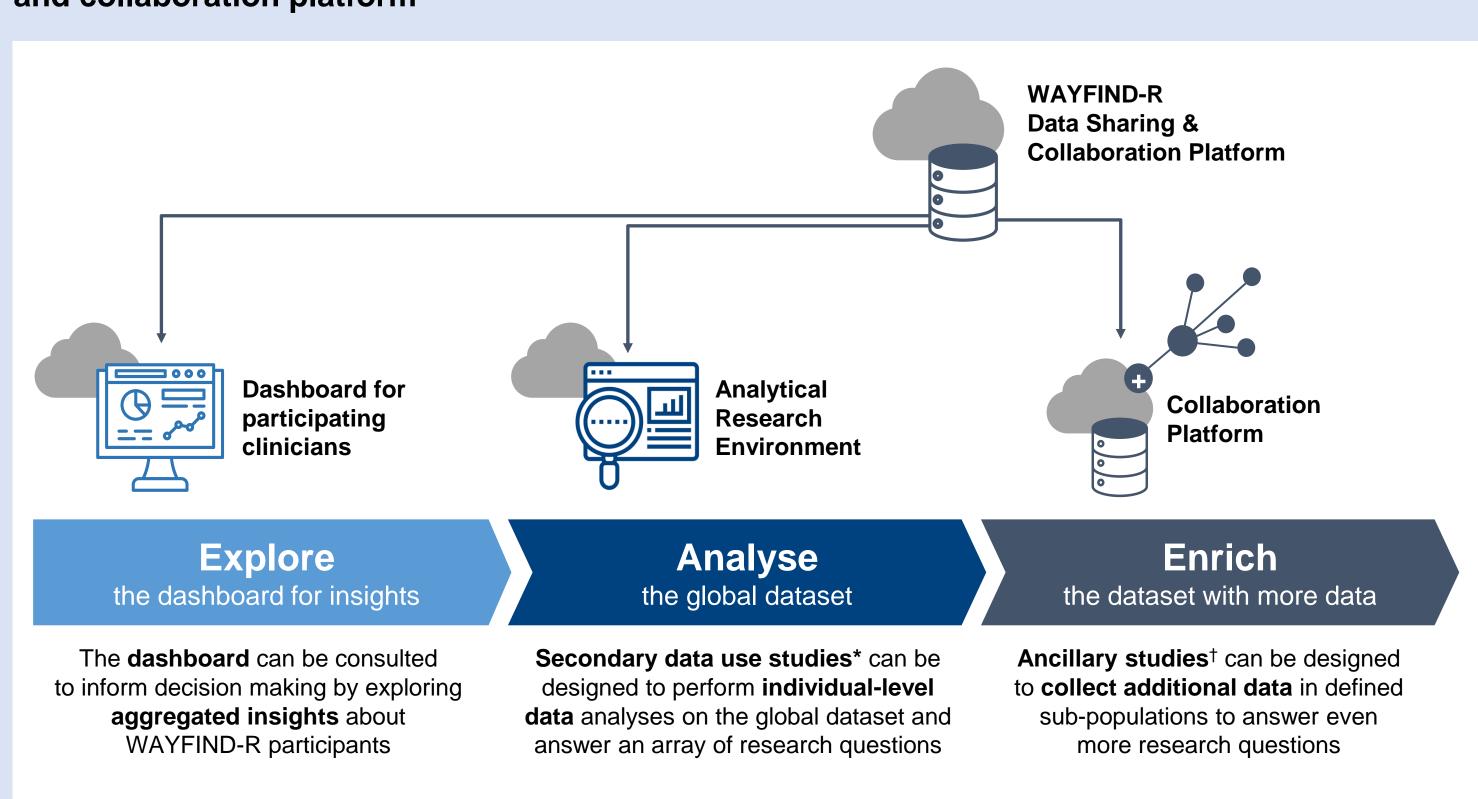
*Includes treatments or medicines that were not part of the standard of care or fell outside the range of services and treatments that are routinely commissioned or provided by the healthcare provider; this typically requires a special request from the treating physician or institution to fund this treatment on an individual basis. †Out-of-pocket payment by the patient. ‡Patient reimbursed for the treatment, either through insurance or via the National Health Service.

Table 3. NGS turnaround times

	Number of patients	Median (days)	IQR (days)	Range (days)	
Test type					
Commercial*	255	13	11–18	2–140	
Local [†]	242	21	11–32	0–705	
Unknown [‡]	63	11	11–22	0–95	
Not available§	111	14	9–19.75	0–112	

*End-to-end services. †Laboratory-developed tests using research use only or commercial kits. ‡NGS test characteristics information was not classified. §Information on NGS test characteristics was missing. IQR, interquartile range; NGS, next-generation sequencing

Figure 2. Access to research-ready data and analytics tools within the WAYFIND-R data-sharing and collaboration platform



Data are anonymised and mapped to OMOP common data model with various cycles of data quality controls. *Applications from academic researchers to request data for a particular secondary data use study will be reviewed by an Independent Data Access Committee. Studies require a separate protocol and statistical analysis plan, ethical and/or health authority review/approval, as per local requirements. †Requires a separate protocol, statistical analysis plan and health authority and/or ethics committee review/approval, as per local requirements. OMOP, Observational Medical Outcomes Partnership.



 The WAYFIND-R database provides insights into some social determinants of health that may influence patient care pathways, from which further epidemiological and health economic studies are encouraged.

Please contact the lead author at a.hackshaw@ucl.ac.uk for permission to reprint and/or distribute. Presented at the ISPOR EU 2023, 12-15 Nov, 2023, Copenhagen, Denmark.

References

1. Le Tourneau C, et al. JCO Precis Oncol 2022; 6:e2200019

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Disclosures

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