

Table 2: Included Study Characteristics

Study	Aim	Design	Population	Data Collection	Key Findings
Bredart, 2017 (France), (41) Good quality	Describe perceived side effect tolerance in P1 trials.	Qualitative	17 patients 12 female, 5 male Aged 41-72 years (median 63) Cancer type: melanoma, breast, nasopharyngeal, cervical, enometrial	Face-to-face semi-structured interviews of open questions.	As trial is last treatment hope, patients accept side-effects, resulting in reduced reporting. Patients stop trial treatment if it stops working rather than side-effects. Disappointed when it is not effective.
Cohen, 2007 (USA), (42) Good quality	Describe the burdens and benefits, as well as perceived QoL, of P1 trial patients.	Mixed methods: Survey with some patients interviewed	16 patients 10 male, 6 female 29 – 69 years (57 mean) Cancer type: solid tumours (not specified)	Face-to-face interviews audiotaped and transcribed.	Patients' QoL was good as they were free from cancer symptoms or drug side-effects. However, the trial process was a huge burden as they were away from home and had to spend a lot of time at the hospital for treatment.
Daugherty, 1995 (USA), (43) Low quality	Understand patient perceptions of P1 trials, and issues related to their participation.	Mixed methods: Survey with both open and closed data	27 patients 19 male, 8 female Aged 32-80 (median 58years) 70% white; 26% African American Cancer type: 15 different diagnoses (not specified)	Structured interviews of open and closed questions. Responses hand-written.	P1 trial participants are strongly motivated by hope of therapeutic benefit and very few patients understand the purpose of P1 as dose-determination studies.
Ferrell, 2019 (USA), (44) Ferrell, 2020 (USA)	Capture patient perspectives of P1 trial participation and disease/treatment options. (44)	Qualitative	30 patients 56.8% female 30.7% ethnic minority	Interviews audio-recorded and transcribed.	Doctors, lack of other options, altruism and family motivate patients to join P1 trial. Patients' expectations of trial are to get better, improve

(45) Good quality	Secondary analysis focused on spiritual needs of this population. (45)		Aged: <40 = 3, 50-59 = 8, 60-69= 9, 70-79= 8, >80=2 Cancer type: lung, bladder, colon, ovarian, prostate, breast, cervical, other		their QoL, and reach remission or cure. These motivations are optimistic not misconceptions.(44) The transition to phase 1 trial participation is a time of balancing hope for extended life with the reality of disease. (45)
Godskesen. 2013 (Sweden), (46) Good quality	Explore patients' reasons for participation in, and experiences of, P1 trial participation.	Qualitative	14 patients Male 9, Female 5 Age: Range 51–81 (Median 63) Cancer type; prostate, melanoma, lung, pancreas	Face-to-face semi-structured interviews audio-recorded and transcribed.	Patients had poor understandings of the trial and demonstrated therapeutic misconception. Hope of trial success was good for patient well-being and mental health. Trial offers patients extra care and attention which was a positive factor.
Kohara, 2010 (Japan), (47) Good quality	Understand the decision-making process in participation of P1 trials	Qualitative	25 patients Male 14, female 11 Age: <50 =5, 50-59 = 7, 60-69 = 10, >70 = 3 Cancer type; colon, lung, breast, head and neck, renal, oesophageal, pancreas, biliary tract, ovary, liposarcoma, thymoma	Face-to-face semi-structured interviews audio-recorded and transcribed.	Decision making depends on: doctors' influence, previous experiences, attitude towards cancer, family (biggest influence)
Kvale, 2010 (USA), (48) Mixed quality	Appreciate the experiences of older adults in P1 trials	Qualitative	4 patients male 3, female 1 Older adults – mean age 63	Face-to-face semi-structured interviews audio-recorded and transcribed.	Patients use social comparison and hope to aid them through the process

			Cancer type; lung, lymphoma, paraganglioma		
Moore, 2000 (UK), (49) Mixed quality	Capture patient perceptions of P1 participation	Qualitative	15 patients 12 female, 3 male Cancer type; 9 different diagnoses (not specified)	Open-questionnaires and an interview audio-taped and transcribed.	Patients felt a need to try everything at any cost. Patients understood the reality of the disease while hoping to be cured. Trial benefits participants and future patients
Pentz, 2012 (USA), (50) Mixed quality	Determine if patients misunderstand trial info and identify those who suffer therapeutic misconception	Mixed methods: Interviews followed by a survey	95 patients 53 male, 42 female median age 57 (range 28–85) 67% white Cancer type: not specified	Interviews audio-record and transcribed.	Therapeutic misconception associated with lower income and higher education. Most participated with hope of direct medical benefit, although other motivations also included: altruism, doctor's recommendation, other collateral benefits of trial.
Reeder-Hayes, 2017 (USA), (51) Good quality	Understand patient decision- making to enter trial	Qualitative	18 patients Female Cancer type: metastatic breast cancer	Telephone semi-structured interviews audio-recorded and transcribed.	Family is a powerful motivating factor, patients join trials for therapeutic gains as well as other factors.
Rodenhuis, 1984 (Netherland)(52) Mixed quality	Explore motives to partake or refuse P1 trial and evaluate quality of consent	Qualitative	10 patients 6 males, 4 female Cancer type: melanoma, head and neck, lung, breast, cervix	Face-to-face interviews.	Many patients did not understand the trial purpose but were motivated by disease improvement and their families.
Schutta, 2000 (USA), (53) Good quality.	Explore factors which influence the decision to join a P1 trial	Qualitative	8 patients Female 5, male 3	2 focus groups. 1st recorded (n=6) and 2 nd (n=2) took notes.	Patients understand the trial purpose but choose to focus on hope of medical benefit.

			Range = 42-72 (years) Cancer type: lung, renal, breast, gastrointestinal		
Sulmasy, 2010 (USA), (54) Good quality.	Explore justifications for estimations of expected therapeutic benefit from p1 trials	Mixed methods	45 patients 23 female, 22 male Mean age 57 Cancer type: not specified	Face-to-face interviews audio-recorded and transcribed.	High hopes of therapeutic benefit had little to do with knowledge and more to do with expressions of optimism.