Additional file 5 Conceptualising patient and public involvement

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Who | Identity | Expertise | Interest in health research | Representation |
| Patient | Service users, consumers, caregivers [1, 4, 15, 16, 43] | Experience-based knowledge of clinical conditions, treatments or care pathways [1] | Interest in full range of health research | Represented as core public in scholarly papers |
| Potential service users [6, 63, 81] | Represented as core public in policy reports |
| Operationalised as individuals or groups (i.e. patient advocacy organisations) |
| Community | Social constituencies – by common history or interest/identity such as gender, race/ethnicity, sexual orientation, illness experience [44] | Collective expertise – derived from historical, cultural, politico-economic conditions | Interest in population health research, e.g. inequities in care, disparities in outcome [51, 61] | Represented as core public in scholarly papers |
| Operationalised as organised or emergent groups, including health, religious or educational organisations [44], civil society organisations or NGOs [38, 41] | To represent a public interest, not the ‘consumer’ of market-based relations [45] | Interest in research beyond health sector for social determinants of health [45] | Generally not identified as core public in policy reports [56] |
| Emphasis on applied, inter-disciplinary research [42, 46] |
| Other | Citizen/Public | | | |
| * Persons with general lay expertise [47] | | | |
| * Includes ‘knowledge users’ such as policy-makers, administrators, community leaders, private sector organisation, etc. [62] | | | |
| Clinician | | | |
| * Key informants regarding service use, alongside patients [47, 48] | | | |