# Supplementary Material

***Search Strategy***

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Database | Platform | Inception | Date of access | Number of results obtained |
| Medline | OvidSP | 1946 | april 2016 | 82 |
| Embase | Elsevier | 1974 | april 2016 | 48 |
| Cinahl | EbscoHOST | 1940 | april 2016 | 33 |
| Science Citation Index Expanded | WOS | 2000 | april 2016 | 38 |
| Cochrane Library | Wiley | 1993 | april 2016 | 84 |
| PsycINFO | EbscoHOST | 1967 | april 2016 | 13 |
| Scopus | Elsevier | 2004 | april 2016 | 45 |
| JSTOR | JSTOR | 1995 | april 2016 | 16 |
| TOTAL (without duplicates) | 211 |

Medline

|  |  |  |
| --- | --- | --- |
| 1 | \*Consumer Participation/ | 8199 |
| 2 | \*Patient Participation/ | 10651 |
| 3 | ((Patient or Consumer or caregiver or client or community or service-user or user or citizen) adj1 (Involvement or Participation or engagement)).tw. | 9797 |
| 4 | 1 or 2 or 3 | 25998 |
| 5 | \*Technology Assessment, Biomedical/ | 4938 |
| 6 | (HTA).tw. | 1872 |
| 7 | (Health Technology adj1 (Assessment or funding or appraisal)).tw | 2767 |
| 8 | 5 or 6 or 7 | 7669 |
| 9 | 4 and 8 | 87 |
| 10 | limit 9 to (english or french or spanish) | 84 |
| 11 | remove duplicates from 10 | 82 |

Embase

|  |  |  |
| --- | --- | --- |
| #9  | #3 AND #7 AND ([english]/lim OR [french]/lim OR [spanish]/lim) AND [embase]/lim | 48 |
| #8  | #3 AND #7 | 76 |
| #7  | #4 OR #5 OR #6 | 8761 |
| #6  | ('health technology' NEAR/1 (assessment OR funding OR appraisal)):ab,ti | 3316 |
| #5  | hta:ab,ti | 3620 |
| #4  | 'biomedical technology assessment'/mj | 3854 |
| #3  | #1 OR #2 | 30323 |
| #2  | ((patient OR consumer OR caregiver OR client OR community OR 'service user' OR user OR citizen) NEAR/1 (involvement OR participation ORengagement)):ab,ti | 11928 |
| #1  | 'consumer'/mj OR 'patient participation'/mj | 20183 |

Cinahl

|  |  |  |
| --- | --- | --- |
| S7 | S3 AND S6 Limitadores - Idioma: English, French, Spanish | (33) |
| S6 | S4 OR S5  | (1,425) |
| S5 | TI ( (('health technology' N1 (assessment OR funding OR appraisal)) ) OR AB ( (('health technology' N1 (assessment OR funding OR appraisal)) )  |  (1,247) |
| S4 | TI ( ('biomedical technology assessment' OR hta) ) OR AB ( ('biomedical technology assessment' OR hta) )  |  (465) |
| S3 | Or/ S1-S2 | (14,031) |
| S2 | TI ( ((Patient or Consumer or caregiver or client or community or service-user or user or citizen) N1 (Involvement or Participation or engagement)) ) OR AB ( ((Patient or Consumer or caregiver or client or community or service-user or user or citizen) N1 (Involvement or Participation or engagement)) )  |  (7,641) |
| S1 | (MM "Consumer Participation")  | (7,788) |

Science Citation Index Expanded

|  |  |  |
| --- | --- | --- |
| #3 | (#2 AND #1) *AND*Idioma: (English OR French OR Spanish) | 38 |
| #2 | ('biomedical technology assessment') *OR* Title: (hta OR health technology assessment OR health technology funding OR health technology appraisal) | 2.052 |
| #1 | ('Consumer Participation' or 'Patient Participation') OR Title: (patient participation OR consumer participation OR caregiver participation OR client participation OR community participation OR service user participation OR user participation OR citizen participation OR patient involvement OR consumer involvement OR caregiver involvement OR client involvement OR community involvement OR service user involvement OR user involvement OR citizen involvement OR patient engagement OR consumer engagement OR caregive engagement OR client engagement OR community engagement OR service user engagement OR user engagement OR citizen engagement) | 36.636 |

COCHRANE

|  |  |  |
| --- | --- | --- |
| #1 | MeSH descriptor: [Consumer Participation] this term only | 243 |
| #2 | MeSH descriptor: [Patient Participation] this term only | 1010 |
| #3 | ('Consumer Participation' or 'Patient Participation' or patient participation or consumer participation or caregiver participation or client participation or community participation or service user participation or user participation or citizen participation or patient involvement or consumer involvement or caregiver involvement or client involvement or community involvement or service user involvement or user involvement or citizen involvement or patient engagement or consumer engagement or caregive engagement or client engagement or community engagement or service user engagement or user engagement or citizen engagement):ti,ab,kw (Word variations have been searched) | 12794 |
| #4 | #1 or #2 or #3  | 12794 |
| #5 | MeSH descriptor: [Technology Assessment, Biomedical] this term only | 607 |
| #6 | ('health technology' near/1 (assessment or funding or appraisal)):ti,ab,kw (Word variations have been searched) | 1167 |
| #7 | 'biomedical technology assessment' or hta:ti,ab,kw (Word variations have been searched) | 1184 |
| #8 | #5 or #6 or #7  | 1785 |
| #9 | #4 and #8 | 84 |

PsycINFO

|  |  |  |
| --- | --- | --- |
| S7 | S3 AND S6 **Limitadores** - Idioma: English, French, Spanish | (13) |
| S6 | S4 OR S5  | (458) |
| S5 | TI ( (('health technology' N1 (assessment OR funding OR appraisal)) ) OR AB ( (('health technology' N1 (assessment OR funding OR appraisal)) )  | (300) |
| S4 | TI ( ('biomedical technology assessment' OR hta) ) OR AB ( ('biomedical technology assessment' OR hta) )  | (257) |
| S3 | S1 OR S2  | (11,725) |
| S2 | TI ( ((Patient or Consumer or caregiver or client or community or service-user or user or citizen) N1 (Involvement or Participation or engagement)) ) OR AB ( ((Patient or Consumer or caregiver or client or community or service-user or user or citizen) N1 (Involvement or Participation or engagement)) )  | (11,020) |
| S1 | MM "Client Participation"  | (1,245) |

Scopus

|  |  |  |
| --- | --- | --- |
| #1 | TITLE-ABS-KEY ( "Patient Participation" AND "Health Technology Assessment" ) AND SUBJAREA ( mult OR medi OR nurs OR vete OR dent OR heal ) AND ( LIMIT-TO ( DOCTYPE , "ar" ) OR LIMIT-TO ( DOCTYPE , "re" ) ) AND ( LIMIT-TO ( LANGUAGE , "English" ) OR LIMIT-TO ( LANGUAGE , "Spanish" ) OR LIMIT-TO ( LANGUAGE , "French" ) ) | 45 |

JSTOR

|  |  |  |
| --- | --- | --- |
| 1 | (( "Patient Participation" AND "Health Technology Assessment" )) | 16 |

***References included in the literature review***

1. Abelson J, Bombard Y, Gauvin FP, Simeonov D, Boesveld S. Assessing the impacts of citizen deliberations on the health technology process. International Journal of Technology Assessment in Health Care 2013;29(3):282-9.
2. Abelson J, Giacomini M, Lehoux P, Gauvin FP. Bringing 'the public' into health technology assessment and coverage policy decisions: from principles to practice. Health Policy 2007;82(1):37-50.
3. Barham L. Public and patient involvement at the UK National Institute for Health and Clinical Excellence. The Patient: Patient-Centered Outcomes Research 2011;4(1):1-10.
4. Bastian H, Scheibler F, Knelangen M, Zschorlich B, Nasser M, Waltering A. Choosing health technology assessment and systematic review topics: the development of priority-setting criteria for patients' and consumers' interests. International Journal of Technology Assessment in Health Care 2011;27(4):348-56.
5. Boivin A, Green J, van der Meulen J, Nolle E. Why Consider Patients' Preferences?: A Discourse Analysis of Clinical Practice Guideline Developers. Medical Care 2009.
6. Buck D, Gamble C, Dudley L, Preston J, Hanley B, Williamson PR, Young B, EPIC Patient Advisory Group, EPIC Patient Advisory Group. From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials. BMJ Open 2014;4(12):e006400.
7. Caron-Flinterman JF, Broerse JEW, Bunders JF. Patient Partnership in Decision-Making on Biomedical Research: Changing the Network. Science, Technology, & Human Values 2007.
8. Danner M, Hummel JM, Volz F, van Manen JG, Wiegard B, Dintsios CM, Bastian H, Gerber A, Ijzerman MJ. Integrating patients' views into health technology assessment: Analytic hierarchy process (AHP) as a method to elicit patient preferences. International Journal of Technology Assessment in Health Care 2011;27(4):369-75.
9. De Wit MPT, Elberse JE, Broerse JEW, Abma TA. Do not forget the professional - the value of the FIRST model for guiding the structural involvement of patients in rheumatology research. Health Expectations 2015.
10. Dipankui MT, Gagnon MP, Desmartis M, Legare F, Piron F, Gagnon J, Rhainds M, Coulombe M. [Patient participation in the assessment of alternatives to restraint and seclusion]. Sante Publique (Vandoeuvre-Les-Nancey) 2014;26(2):217-26.
11. Dipankui MT, Gagnon MP, Desmartis M, Legare F, Piron F, Gagnon J, Rhiands M, Coulombe M. Evaluation of patient involvement in a health technology assessment. International Journal of Technology Assessment in Health Care 2015;31(3):166-70.
12. Dirksen CD. The use of research evidence on patient preferences in health care decision-making: Issues, controversies and moving forward. Expert Rev Pharmacoecon Outcomes Res. 2014;14(6):785-94
13. Douglas CMW, Wilcox E, Burgess M, Lynd LD. Why orphan drug coverage reimbursement decision-making needs patient and public involvement. Health Policy 2015.
14. Einsiedel EF, Ross H. Animal spare parts? A Canadian public consultation on xenotransplantation. Science & Engineering Ethics 2002;8(4):579-91.
15. Entwistle VA, Watt IS, Davis H, Dickson R, Pickard D, Rosser J. Developing information materials to present the findings of technology assessments to consumers. The experience of the NHS Centre for Reviews and Dissemination. International Journal of Technology Assessment in Health Care 1998;14(1):47-70.
16. Facey K, Boivin A, Gracia J, Hansen HP, Lo SA; Mossman J, Single A. Patients' perspectives in health technology assessment: a route to robust evidence and fair deliberation. International Journal of Technology Assessment in Health Care 2010;26(3):334-40.
17. Fattal J, Lehoux P. Health technology assessment use and dissemination by patient and consumer groups: why and how? International Journal of Technology Assessment in Health Care 2008;24(4):473-80.
18. Gagnon MP; Candas B; Desmartis M; Gagnon J; La Roche D; Rhainds M; Coulombe M; Dipankui MT; Legare F. Involving patient in the early stages of health technology assessment (HTA): a study protocol. BMC Health Services Research 2014;14:273.
19. Gagnon MP, Desmartis M, Dipankui MT, Gagnon J, St Pierre M. Alternatives to seclusion and restraint in psychiatry and in long-term care facilities for the elderly: perspectives of service users and family members. The Patient: Patient-Centered Outcomes Research 2013;6(4):269-80.
20. Gagnon MP, Desmartis M, Gagnon J, St Pierre M, Gauvin FP, Rhainds M, Lepage-Savary D, Coulombe M, Dipankui MT, Legare F. Introducing the patient's perspective in hospital health technology assessment (HTA): the views of HTA producers, hospital managers and patients. Health Expectations 2014;17(6):888-900.
21. Gagnon MP, Desmartis M, Gagnon J, St Pierre M, Rhainds M, Coulombe M, Tantchou MD, Legare F. Framework for user involvement in health technology assessment at the local level: Views of health managers, user representatives, and clinicians. International Journal of Technology Assessment in Health Care 2015;31(1-2):68-77.
22. Gagnon MP, Desmartis M, Lepage-Savary D, Gagnon J, St Pierre M, Rhainds M, Lemieux R, Gauvin FP, Pollender H, Legare F. Introducing patients' and the public's perspectives to health technology assessment: A systematic review of international experiences. International Journal of Technology Assessment in Health Care 2011.
23. Gagnon MP, Lepage-Savary D, Gagnon J, St Pierre M, Simard C, Rhainds M, Lemieux R, Gauvin FP, Desmartis M, Legare F. Introducing patient perspective in health technology assessment at the local level. BMC Health Services Research 2009;9:54.
24. Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. 'It all depends': conceptualizing public involvement in the context of health technology assessment agencies. Social Science & Medicine 2010;70(10):1518-26.
25. Gauvin FP, Abelson J, Giacomini M, Eyles J, Lavis JN. Moving cautiously: Public involvement and the health technology assessment community. International Journal of Technology Assessment in Health Care 2011;27(1):43-9.
26. Guston DH. Participating despite questions: toward a more confident participatory technology assessment: commentary on: 'Questioning 'participation': a critical appraisal of its conceptualization in a Flemish participatory technology assessment'. Science & Engineering Ethics 2011;17(4):691-7.
27. Hailey D, Nordwall M. Survey on the involvement of consumers in health technology assessment programs. International Journal of Technology Assessment in Health Care 2006;22(4):497-9.
28. Hailey D, Werko S, Bakri R, Cameron A, Gohlen B, Myles S, Pwu J, Yothasamut J. Involvement of consumers in health technology assessment activities by Inahta agencies. International Journal of Technology Assessment in Health Care 2013;29(1):79-83.
29. Hansen HP, Draborg E, Kristensen FB. Exploring qualitative research synthesis: the role of patients' perspectives in health policy design and decision making. The Patient: Patient-Centered Outcomes Research 2011;4(3):143-52.
30. Hansen HP, Lee A, Randwijk CB. Patient aspects: a review of fifty-eight Danish HTA reports. International Journal of Technology Assessment in Health Care 2011.
31. Ijzerman MJ, van Til JA, Bridges JF. A comparison of analytic hierarchy process and conjoint analysis methods in assessing treatment alternatives for stroke rehabilitation. The Patient: Patient-Centered Outcomes Research 2012;5(1):45-56.
32. Izquierdo F, Gracia J, Guerra M, Blasco JA, Andradas E; Health technology assessment-based development of a Spanish breast cancer patient decision aid. International Journal of Technology Assessment in Health Care 2011;27(4):363-8.
33. Johanson R, Rigby C, Newburn M, Stewart M, Jones P. Suggestions in maternal and child health for the National Technology Assessment Programme: a consideration of consumer and professional priorities. Journal of the Royal Society for the Promotion of Health 2002;122(1):50-4.
34. Kinter ET, Schmeding A, Rudolph I, dosReis S, Bridges JF. Identifying patient-relevant endpoints among individuals with schizophrenia: an application of patient-centered health technology assessment. International Journal of Technology Assessment in Health Care 2009.
35. Kleme J, Pohjanoksa-M, Airaksinen M, Enlund H, Kastarinen H, Peura P, Hmeen-Anttila K. Patient perspective in health technology assessment of pharmaceuticals in Finland. Int J Technol Assess Health Care. 2014;30(3):306-11.
36. Kreis J, Schmidt H. Public engagement in health technology assessment and coverage decisions: a study of experiences in France, Germany, and the United Kingdom. Journal of Health Politics, Policy & Law 2013;38(1):89-122.
37. Lee A, Skött LS, Hansen HP. Organizational and patient-related assessments in HTAs: State of the art. Int J Technol Assess Health Care. 2009;25(4):530-6.
38. Lopes E, Carter D, Street J. Power relations and contrasting conceptions of evidence in patient-involvement processes used to inform health funding decisions in Australia. Social Science & Medicine 2015;135:84-91.
39. Lopes E, Street J, Carter D, Merlin T. Involving patients in health technology funding decisions: stakeholder perspectives on processes used in Australia. Health Expectations 1919.
40. Mathiesen TP, Willaing I, Freil M, Jorgensen T, Andreasen AH, Ladelund S, Harling H. How do patients with colorectal cancer perceive treatment and care compared with the treating health care professionals? Medical Care 2007.
41. McGregor M, Brophy JM. End-user involvement in health technology assessment (HTA) development: a way to increase impact. International Journal of Technology Assessment in Health Care 2005;21(2):263-7.
42. Menon D, Stafinski T. Engaging the public in priority-setting for health technology assessment: findings from a citizens' jury. Health Expectations 2008;11(3):282-93.
43. Menon D, Stafinski T. Role of patient and public participation in health technology assessment and coverage decisions. Expert Review of Pharmacoeconomics & Outcomes Research 2011;11(1):75-89.
44. Messina J, Grainger DL. A pilot study to identify areas for further improvements in patient and public involvement in health technology assessments for medicines. The Patient: Patient-Centered Outcomes Research 2012;5(3):199-211.
45. Moran R, Davidson P. An uneven spread: a review of public involvement in the National Institute of ealth Research's Health Technology Assessment program. International Journal of Technology Assessment in Health Care 2011;27(4):343-7.
46. Moreira T. Understanding the role of patient organizations in health technology assessment. Health Expectations 2015;18(6):3349-57.
47. Oliver S, Clarke JL, Rees R, Milne R, Buchanan P, Gabbay J, Gyte G, Oakley A, Stein K. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. Health Technology Assessment 2004.
48. Oliver S, Milne R, Bradburn J, Buchanan P, Kerridge L, Walley T, Gabbay J. Involving consumers in a needs-led research programme: a pilot project. Health Expectations 2001;4(1):18-28.
49. Ong BN. The lay perspective in health technology assessment. International Journal of Technology Assessment in Health Care 1996;12(3):511-7.
50. Pivik J, Rode E, Ward C. A consumer involvement model for health technology assessment in Canada. Health Policy 2004;69(2):253-68.
51. Single ANV, Scott AM, Wale J. Developing Guidance on Ethics for Patient Groups Collecting and Reporting Patient Information for Health Technology Assessments. The Patient - Patient-Centered Outcomes Research 2016;9(1):1-4.
52. Stafinski T, Menon D, Yasui Y. Assessing the impact of deliberative processes on the views of participants: is it 'in one ear and out the other'? Health Expectations 2014;17(2):278-90.
53. Staniszewska S, Brett J, Mockford C, Barber R. The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. International Journal of Technology Assessment in Health Care 2011;27(4):391-9.
54. Street JM, Braunack-Mayer AJ, Facey K, Ashcroft RE, Hiller JE. Virtual community consultation? Using the literature and weblogs to link community perspectives and health technology assessment. Health Expectations 2008.
55. Tallon D, Chard J, Dieppe P. Exploring the priorities of patients with osteoarthritis of the knee Arthritis Care and Research 2000.
56. van Oudheusden M. Questioning 'participation': a critical appraisal of its conceptualization in a Flemish participatory technology assessment. Science & Engineering Ethics 2011;17(4):673-90.
57. Wahlster P, Goetghebeur M, Schaller S, Kriza C, Kolominsky-Rabas P. Exploring the perspectives and preferences for HTA across German healthcare stakeholders using a multi-criteria assessment of a pulmonary heart sensor as a case study. Health Research Policy and Systems 2015.
58. Whitaker R, Hendry M, Booth A, Carter B, Charles J, Craine N, Edwards RT, Lyons M, Noyes J, Pasterfield D, Rycroft-Malone J, Williams N. Intervention Now To Eliminate Repeat Unintended Pregnancy in Teenagers (INTERUPT): a systematic review of intervention effectiveness and cost-effectiveness, qualitative and realist synthesis of implementation factors and user engagement. BMJ Open 2014;4(4):e004733.

***Additional references identified by manual search***

1. Amis L, Livingstone H. Technology Appraisal Patient Expert Survey 2012 Report. NICE 2014
2. Boivin A, Lehoux P, Burgers J, Grol R. What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation. Milbank Q. 2014;92(2):319-50.
3. Brettschneider C, Lähmann D, Raspe H. Informative value of Patient Reported Outcomes (PRO) in Health Technology Assessment (HTA). GMS Health Technol Assess. 2011;7:Doc01.
4. Brooker AS, Carcone S, Witteman W, Krahn M. Quantitative patient preference evidence for health technology assessment: a case study. Int J Technol Assess Health Care. 2013;29(3):290-300.
5. Carman KL, Mallery C, Maurer M, Wang G, Garfinkel S, Yang M, Gilmore D, Windham A, Ginsburg M, Sofaer S, Gold M, Pathak-Sen E, Davies T, Siegel J, Mangrum R, Fernandez J, Richmond J, Fishkin J, Siu Chao A. Effectiveness of public deliberation methods for gathering input on issues in healthcare: Results from a randomized trial. Social Science & Medicine 2015;133:11-20.
6. Christiaens W, Kohn L, Léonard C, Denis A, Daue F, Cleemput I. Models for citizen and patient involvement in health care policy - Part I: exploration of their feasibility and acceptability. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE). 2012. KCE Reports 195C. D/2012/10.273/105.
7. Degeling C, Carter S, Rychetnik L. Which public and why deliberate? – A scoping review of public deliberation in public health and health policy research. Social Science & Medicine 2015;131:114-121
8. DeJean D, Giacomini M, Simeonov D, Smith A. Finding Qualitative Research Evidence for Health Technology Assessment. Qualitative Health Researh 2016;26(10):1307-17.
9. den Breejen E, Nelen W, Knijnenburg J, Burgers J, Hermens R, Kremer J. Feasibility of a wiki as a participatory tool for patients in clinical guideline development. Journal of medical Internet research 2012;14(5):e138.
10. EUnetHTA. Core Model Version 3.0 for the full assessment of Diagnostic Technologies, Medical and Surgical Interventions, Pharmaceuticals and Screening Technologies 2016.
11. EUnetHTA. Stakeholder forum. [Internet]. Available in: <http://eunethta.eu/#tab-3-tab>
12. European commission. HTA network working group on multiannual work programme. 2016. Available in: [ec.europa.eu/health/sites/health/files/technology\_assessment/docs/2016\_2020\_pgmnetwork\_en.pdf](https://ec.europa.eu/health/sites/health/files/technology_assessment/docs/2016_2020_pgmnetwork_en.pdf)
13. European Patient Forum. Patient involvement in health technology assessment. Available in: [www.eu-patient.eu/globalassets/projects/hta/hta-epf-final-report2013.pdf](http://www.eu-patient.eu/globalassets/projects/hta/hta-epf-final-report2013.pdf)
14. Facey K. Understanding Health Technology Assessment (HTA). Health Equallity Europe 2008
15. Gauvin FP, Abelson J, Lavis JN. Evidence Brief: Strengthening Public and Patient Engagement in Health Technology Assessment in Ontario. Hamilton, Canada: McMaster Health Forum, 2014.
16. Guideline International Network (GIN) Patient and Public Involvement Working Group. GIN Public toolkit: Patient and Public Involvement in Guidelines. [Internet]. Available in: https://www.g-i-n.net/document-store/working-groups-documents/g-i-n-public/toolkit/toolkit-2015
17. Grupo de trabajo de implicación de pacientes en el desarrollo de GPC. Implicación de Pacientes en el Desarrollo de Guías de Práctica Clínica: Manual Metodológico. Ministerio de Sanidad, Servicios Sociales e Igualdad. Instituto Aragonés de Ciencias de la Salud-IACS. Guías de Práctica Clínica en el SNS: IACS No 2010/01.
18. Hämeen-Anttila K, Komulainen J, Enlund H, Mäkelä M, Mäkinen E, Rannanheimo P, Sipilä R. Incorporating patient perspectives in health technology assessments and clinical practice guidelines. [Res Social Adm Pharm](https://www.ncbi.nlm.nih.gov/pubmed/26778190%22%20%5Co%20%22Research%20in%20social%20%26%20administrative%20pharmacy%20%3A%20RSAP.) 2016;12(6):903-913.
19. Hermosilla-Gago T, Grupo de Expertos de las Agencias de Evaluación de Tecnologías Sanitarias de España. Manual para adaptar informes de evaluación de tecnologías sanitarias a los ciudadanos. Sevilla: Agencia de Evaluación de Tecnologías Sanitarias de Andalucía. Consejería de Salud. Junta de Andalucía y Ministerio de Sanidad y Consumo; 2011.
20. International Network of Agencies for Health Technology, Assessment (INATHA). Patient Submission Templates for HTA–Call forPiloting / Consultation. INATHA 2015. Available in: <http://www.inahta.org/2014/07/patient-templates/>
21. INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh 2012. Available in: <http://www.invo.org.uk/resource-centre/resource-for-researchers/>
22. INVOLVE. Exploring public involvement in research funding applications. [Internet]. Available in: <http://www.invo.org.uk/resource-centre/examples/exploring-public-involvement-in-nihr-research-funding-applications/>
23. INVOLVE. Exploring the impact: examples. [Internet]. Available in: <http://www.invo.org.uk/resource-centre/examples/>
24. INVOLVE. Guidance on payment for involvement. [Internet]. Available in: <http://www.invo.org.uk/posttypepublication/payment-for-involvement/>
25. INVOLVE. Online PPI cost calculator. [Internet]. Available in: <http://www.invo.org.uk/resource-centre/involvement-cost-calculator/>
26. INVOLVE. Public involvement in research: impact on ethical aspects of research. [Internet]. Available in: <http://www.invo.org.uk/posttypepublication/public-involvement-in-researchimpact-on-ethical-aspects-of-research/>
27. Kelson M, Akl EA, Bastian H, Cluzeau F, Curtis JR, Guyatt G, Montori VM, Oliver S, Schünemann HJ; ATS/ERS Ad Hoc Committee on Integrating and Coordinating Efforts in COPD Guideline Development. Integrating values and consumer involvement in guidelines with the patient at the center: article 8 in Integrating and coordinating efforts in COPD guideline development. An official ATS/ERS workshop report. Proc Am Thorac Soc. 2012;9(5):262-8.
28. Kelson, M. The NICE patient involvement unit. Evidence-based healthcare and public health. 2005;9(4), 304-307.
29. MacLean S, Mulla S, Akl EA, Jankowski M, Vandvik PO, Ebrahim S, McLeod S, Bhatnagar N, Guyatt GH. Patient Values and Preferences in Decision Making for Antithrombotic Therapy: A Systematic Review. Chest. 2012;141(2 Suppl):e1S-e23S.
30. Moran R, Davidson P. An uneven spread: a review of public involvement in the National Institute of Health Research's Health Technology Assessment program. Int J Technol Assess Health Care. 2011;27(4):343-7.
31. Morrison C, Dearden A. Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design. Health Policy. 2013;112(3):179-86.
32. NICE. Positively equal: a guide to addressing equality issues in developing NICE clinical guidelines. Guidance and guidelines NICE 2012.
33. OHTAC Public Engagement Subcommittee. Public Engagement for Health Technology Assessment at Health Quality Ontario—Final Report From the Ontario Health Technology Advisory Committee Public Engagement Subcommittee [Internet]. Public Engagement for HTA at HQO—Final Report from the OHTAC Public Engagement Subcommittee; 2015. Available in: <http://www.hqontario.ca/Portals/0/documents/evidence/special-reports/report-subcommittee-20150407-en.pdf>
34. Oliver S, Armes DG, Gyte G. Public Involvement in Setting a National Research Agenda A Mixed Methods Evaluation. Patient. 2009 Sep 1;2(3):179-9.
35. Popay J, Collins M (editors), PiiAF Study Group. The Public Involvement Impact Assessment Framework Guidance. Universities of Lancaster, Liverpool and Exeter. 2014. Available in: <http://piiaf.org.uk/>
36. Puñal-Riobóo J, Baños Álvarez E, Varela Lema L, Castillo Muñoz MA, Atienza Merino G, Ubago Pérez R, Triñanes Pego Y, Molina López T y López García M en representación del Grupo de trabajo de la Guía para la elaboración y adaptación de informes rápidos de evaluación de tecnologías sanitarias. Red Española de Agencias de Evaluación de Tecnologías Sanitarias y Prestaciones del SNS. Agencia Gallega para la Gestión del Conocimiento en Salud. Unidad de Asesoramiento Científico-técnico, avalia-t; 2016.
37. Rodríguez MG, Espallargues M. Incorporación de pacientes, cuidadores y población en general en la evaluación de tecnologías sanitarias (ETS): experiencias de agencias y unidades de ETS en España. Barcelona: Agència de Qualitat i Avaluació Sanitàries de Catalunya, 2014.
38. Rowe G, Frewer LJ. Public Participation Methods: A Framework for Evaluation. Science, Technology, & Human Values 2000;25(1):3-29.
39. Royle J, Oliver S. Consumer involvement in the health technology assessment program. Int J Technol Assess Health Care. 2004;20(4):493-7.
40. SECOR. CADTH Patient Input Process Review. Findings and Recommendations. 2012. Available in: <https://www.cadth.ca/sites/default/files/pdf/2012_SECOR_Patient-Input-Review_e.pdf>
41. Staley K, Doherty C. It’s not evidence, it’s insight: bringing patients’ perspectives into health technology appraisal at NICE. Research Involvement and Engagement 2016;2(1):4.
42. Wortley S, Tong A, Howard K. Community views and perspectives on public engagement in health technology assessment decision making. Aust Health Rev. 2017;41(1):68-74.
43. Wortley S, Tong A, Howard K. Preferences for engagement in health technology assessment decision-making: a nominal group technique with members of the public. BMJ Open. 2016;6(2):e010265.

**Difficulty of participation activities of patients, caregivers and users**

*Question 4: The tasks that patients, caregivers and users could perform to participate in the different phases of HTA are listed in detail below. The most important activities of each phase are presented in sequential order. We hope that you can assess the possibility and degree of difficulty that participation in each of these activities would have for your organization.*

*Please rate the difficulty of participation in each of these activities, taking into account the following criteria:*

* *Low difficulty: we could do it in our organization autonomously with the available resources.*
* *Medium difficulty: we could do it with some extra technical support.*
* *High difficulty: it is difficult to find the time and resources to do this.*