

The following tables summarises the quotations extracted from papers divided and classified in the three levels above specified and distinguishing between research-phase stages, facilitators and barriers:

Table 1 - Factors to be considered for engaging communities and persons in co-production for health research and innovation at research-institutional level

Design and recruitment phase		
Facilitators	(i) the researcher's <b>commitment to an ethical, respectful process</b> . <b>reflexive</b> response <b>rapport</b> building	
	(p) "collaborative researchers" as available <b>experts</b> with good <b>social skills</b> . <b>sincere concern</b> the need for <b>training</b> CBOs in research methods.	
	(b) The <b>time required to complete the ethical and administrative approval process</b> at health authorities <b>sociopolitical</b> environment. perceived <b>lack of opportunity</b> to work with people affected by HIV	
Barriers	(l) funding agencies did not have sufficient <b>resources</b> to support researchers <b>not familiar</b> with patient involvement in agenda setting researchers often <b>lacked the expertise to involve</b> patients in their research	
	(m) <b>publication pressures</b> <b>lack of funding</b> <b>Overseeing quality control</b>	
	(o) <i>the person [researcher recruiting or investigating] was a same color.</i>	
	(p) lack of <b>training</b> and experience There's an <b>unfortunate disconnect</b> between the world of <b>academia</b> and the world of <b>day- to-day practice</b>	
	(q) getting the <b>right people engaged</b> difficult <b>target population</b> unable to get <b>enough early engagement</b> to inform changes to study design conflict of <b>roles</b> stress about <b>funding/paying</b> contributors for their time disagreement with <b>funders</b> regarding contributor's activities meetings <b>attendance</b>	
	Engagement and co-production phases	
	Facilitators	(j) The methods used for consultations varied across the region and included <b>open forums, attendance at health practitioner meetings, training sessions, small group sessions for community groups, health facilities, and GPs</b> and in some instances <b>1-to-1 meetings</b> with interested individuals
		(r) <b>Organizational commitment</b> <b>PPE being built into policies; having dedicated staff and money for on-going, formal PPE</b> <b>Changing NHS philosophy</b> <b>budget, resources, time and training</b> , embedding PPE in work structures, philosophies and strategies
		(e) <b>A shift in thinking that led teams to feel comfortable about and value the exchange of ideas</b> sites exchanged ideas around: <b>cost neutral ways of improving services</b> , usually involving <b>process changes; coordinated working</b> between secondary, community and primary care; and ways of <b>increasing the potential for dialogue</b> with commissioners and managers <b>enhanced team working.</b> enhanced team morale validating and reassuring experience A number of participants said they found it useful being <b>evaluated by a team with a "fresh eye"</b> . important change in <b>cultural behaviour</b> leading to the adoption of new ideas and additional change
		(a) patients were referred to <b>generically, collectively, and passively,</b>
(e) <i>We haven't really implemented any changes since the NCRP, in all fairness</i> <i>I don't think we've changed anything at the moment, if I'm absolutely honest</i>		
(k) <i>A lot of them come with their personal experiences: they cannot put them behind them and constantly interrupt and yet in a professional setting people have to put all their personal stuff behind them, don't they?</i>		
Barriers	(q) meetings <b>attendance</b> during the interview the researcher spoke of his initial ' <b>tokenism</b> ' and ' <b>ignorance</b> ' about how PPI ' <b>should and could work</b> '	

Table 2 - Factors to be considered for engaging communities and persons in co-production for health research and innovation at community level

Design and recruitment phase	
Facilitators	(l) <b>comoderating, reporting</b> back or becoming <b>coauthors</b> Involve partners <b>right from the start</b> Provide <b>background information</b> in <b>understandable</b> language Treat all team members <b>equally</b> promote <b>open dialogue</b>
	(m) <b>scientific integrity</b> was maintained when the community had more ownership and participation open <b>communication</b> <b>return results</b> to the community

		<p><b>communicate</b> about the project's <b>progress</b> in a <b>timely</b> fashion</p> <p><b>mutual respect</b></p> <p><b>shared work balance</b></p> <p><b>formal agreement</b></p> <p><b>Training</b></p> <p><b>hands-on experiential training</b></p>
	(q)	<p>The views gathered in these groups will <b>inform the development of research</b> procedures (eg, consent, outcome measures), tools for <b>data collection</b> and the <b>process evaluation</b>.</p> <p>In the trial the groups will be asked to help <b>with development of info leaflets, consent forms, letters, questionnaire</b> design.</p> <p><b>key stakeholders</b></p>
	(r)	<p>More meaningful engagement methods were thought to <b>provide ownership, by empowering individuals</b></p>
	(s)	<p>a broader definition of the agenda created more opportunities for <b>multidisciplinary</b> collaboration</p> <p><b>strong and enduring relationship</b> with <b>shared goals</b></p> <p>Pay <b>deliberate attention to patient issues</b></p> <p>Request <b>lay summary</b> in proposals</p> <p><b>Inform and train researchers</b> about working with patient</p> <p><b>Evaluate patient involvement</b></p> <p><b>Disseminate evaluation</b> to broad public [and] to patients community</p>
	(t)	<p><b>Trust-building</b></p> <p><b>bidirectional sharing of information</b></p> <p>participation in <b>all stages</b> of research</p> <p><b>sharing</b> information with the community</p> <p><b>structural change</b></p> <p><b>equalize the power dynamics</b> between the community and researchers.</p> <p>researchers should be thinking... 'What's the <b>policy implication?</b>' or 'What's the <b>program implication?</b>'</p> <p>sharing of <b>financial resources</b>.</p>
Barriers	(b)	<b>conflicting political agendas</b>
	(k)	marginalisation of <b>experiential</b> narratives
	(m)	<b>long-term commitment</b>
		<b>slow-moving nature</b>
	(p)	<b>further stereotyped, further marginalized, further demonized</b>
		a lot of meeting <b>time</b>
		a lot of staff <b>resources</b>
		<b>we're not reimbursed for that.</b>
		<b>imbalance of power</b>
		<i>the researcher wanted so much <b>control</b></i>
(t)	<p><b>apprehensive</b> about working with researchers.</p> <p>lack of investment in building trust</p> <p>the researcher had <b>overstepped boundaries</b></p> <p>lack of <b>awareness about the needs of study participants</b></p> <p><i>I don't know that I can be sure that the participants are not going to be <b>exploited</b></i></p> <p><i>you served at <b>the mercy of the master...</b> the academic center...</i></p> <p><b>lack of communication</b> contributed to a power imbalance</p> <p><b>lack of sharing information fostered distrust</b></p> <p><b>Fear</b></p>	
Engagement and co-production phases		
Facilitators	(g)	<p>to use <b>terms</b> appropriate to the community in framing questions – <b>Cultural/linguistic competence</b></p> <p>providers have to meet the <b>needs</b> and the level of <b>understanding</b> of the community.</p> <p>Development of <b>community structures</b> involving them through active participation</p>
	(l)	<p>Long-term financial and organisational commitment</p> <p>Acknowledgement of contributions</p> <p>Multistakeholder approach</p> <p>Open dialogue ... Clear communication</p>
	(m)	<p>formal agreements were in place describing the data collection protocol</p> <p>data storage and data sharing</p> <p>financial transparency,</p>
	(p)	<p>"collaborative researchers" as <b>available</b> experts with <b>good social skills</b>.</p> <p>the collaboration was most successful when the researcher was an <b>expert</b> in her or his field</p> <p>made sure that we were doing it in a <b>rigorous</b> way</p> <p><b>reputation</b></p> <p><b>scientific resources</b></p> <p><b>practical application, which was very important to us,</b></p> <p><b>trust</b></p>
	(q)	<p><b>contributed to the development of the application, trial design and study documentation</b></p> <p><b>Early engagement and appreciation that their input</b> into the question is really important</p> <p><b>more involvement at the front end, less in the middle and more at the end</b></p>
	(s)	<p>In three projects patient <b>research partners were engaged in the research team</b></p>

		along-the-way <b>trust</b> was build up among a vast group of patients who became <b>owners of the agenda</b> .
		inclusion of patient representatives in programme committees.
		a <b>broader definition of the agenda</b> created more opportunities for multidisciplinary collaboration
		Patient organizations and researchers can also act as ambassadors and lobby for certain topics.
		<b>Open attitude</b> towards
		<b>Willingness</b> towards
		Adequate <b>resources</b>
		<b>Expertise</b>
		<b>Collaboration</b> between fund and patient organization with middle and long-term goals
		Appoint <b>policy maker</b> for inclusion patient perspective
		appoint <b>patient representative</b> to work with fund
		Include patient representatives in program <b>committee</b>
		identify <b>priorities</b> based on research <b>agenda</b>
		Organize <b>pool of patient research partners</b>
Barriers	(v)	someone with <b>credibility</b> , and they need to say which organization they represent
	(x)	<b>Trust</b>
		Aboriginal staff and clients were more <b>willing to accept anecdotal data</b> (eg, stories) on 'face value'.
		relationship with the local community
		<b>culturally appropriate research materials</b>
		<b>staff they knew and trusted</b>
	(f)	community members whose participation was initially more <b>passive</b> or <b>tokenistic</b>
		pressure to maintain <b>funding</b> to "keep the doors open"
		<b>Participation, although initially high, dwindled</b> until during the final days when no youth participated
	(o)	<i>no one ever asks the people</i>
(p)	<i>He [the researcher] has <b>terrific people skills</b></i>	
	<i>"How many sexual partners have you had in your entire life?" It was <b>intrusive</b>, and our staff didn't like it</i>	
(r)	PPE methods were often described as either <b>tokenistic</b> (e.g. consultation or audit)	
	<b>stigma</b>	
	<b>ethnic/religious barriers</b> limit LGBT involvement	
	patients have <b>other commitments</b>	
	<b>more urgent needs</b>	
	<i>I think most people who are ill just want to get better, they don't want to get political...</i>	
(s)	<i>the fact that you do not have <b>enough people</b> [to carry out those plans]</i>	
	<b>enthusiastic</b> , but did not know what to expect and what aspects required specific attention.	
(t)	<b>apprehensive</b> about working with researchers	
	<b>distrustful</b> of future interactions with researchers.	
	lack of understanding of study participants' needs	
	<b>feeling of discomfort</b>	
	<i>There is <b>no real quid pro quo</b> in the relationship between academic centres and community people.</i>	
(v)	people need to feel like their privacy is not being threatened.	
	<i>It takes a while to build trust,</i>	
(x)	held scepticism towards academics who they felt were promoting their own career	
	using data collected from the ACCHS without acknowledging or giving back to the community	

Table 3 - Factors to be considered for engaging communities and persons in co-production for health research and innovation at individual level

<b>Design and recruitment phase</b>		
Facilitators	(q)	flexibility
Barriers	(c)	desire to limit contact <b>with government authorities</b>
		<b>punitive policy</b> and <b>legal environments</b>
	(d)	<b>difficulty in determining their experiences</b> (...) <b>hesitated</b> (...) changed their answer
	(i)	The research questions elicited numerous ' <b>sensitive</b> ' disclosure
	(q)	some less able to <b>articulate their views</b>
		some wanting to do <b>something impossible</b>
	lack of <b>confidence</b> about contributing at meetings	
	not realising how much <b>training</b> the panel might need	
	Jargon	
<b>Engagement and co-production phases</b>		
Facilitators	(i)	ethical, respectful process.
		<b>Care in word choice</b>
		<b>time to recall and represent their experiences in an unhurried manner</b>
		the writing enabling a reflective process (...) <b>without having to manage emotions</b> .
		<b>anonymity</b> so you can be perhaps a bit more forthright/honest than face to face
	(l)	Respect of confidentiality
	Sensitivity to patient value	

		<b>structural involvement</b> , the relationship between partners and researchers has developed into equal collaboration	
		Participants have tended to <b>raise the level of competencies required</b>	
		feel <b>confident enough</b> to say something	
		could all <b>interact and see each other</b>	
		Especially for somebody like me with a hearing <b>disability</b> it is important to see all the faces’.	
		Tailor support to the competencies of the partners	
		<ul style="list-style-type: none"> <li>▶ Provide lay summaries</li> <li>▶ Create a learning environment: provide training opportunities</li> <li>▶ Distribute reading materials before meetings</li> <li>▶ Explain jargon without being asked</li> <li>▶ Provide glossaries, journals and websites</li> <li>▶ Help partners access and judge scientific literature</li> </ul>	
		Be alert for sensitive issues	
		<ul style="list-style-type: none"> <li>▶ Partners want to be regarded as individuals, from a holistic perspective</li> <li>▶ Try to be inclusive</li> <li>▶ Respect confidentiality and apply ethical rules</li> <li>▶ Acknowledge contributions</li> </ul>	
	(r)	Training for patients to prepare them for involvement	
	(u)	<b>mutual respect</b> and <b>acknowledgement</b> between service users and providers. be to <b>be heard, seen, and valued</b> .	
	(c)	<b>rapport</b>	
		<b>meaningful relationships with research</b> teams	
	Barriers	(c)	High levels of mobility and the relatively short duration of stay unique structural circumstances faced by migrant workers (e.g., social isolation, lack of work authorization) HIV testing offered through research studies also carried potentially negative consequences
		(h)	terms such as ‘selfish’ to describe their motivation
(i)		having to <b>manage emotions</b> . <i>I didn’t have <b>body language interfering</b> like it can sometimes...or have <b>anyone interrupting me</b></i> <b>intrusiveness</b> of body language potential <b>disruptiveness</b> of the interviewer to her train of thought	
(k)		<i>The only thing that we’ve got to bring to it (is) our own experiences</i>	
(l)		Intensity of the programme <b>Physically challenging</b> <b>Accessibility</b> <b>Mentally challenging</b> <b>Language and terminology</b> <b>tokenism</b> Scepticism (..) <b>Imperceptibility of contributions</b> felt <b>ignored, frustrated</b> or <b>unable</b> to contribute. <b>language</b> was also a barrier for some whose first language is not English. Moderators’ behaviour was sometimes considered <b>unethical</b> or to be a <b>poor approach to sensitive issues</b> . Not involved from the beginning Lack of information Power imbalance	
(q)		lack of <b>engagement</b> just being <b>confident enough to make your point</b> <b>not knowing what was expected of them and of feeling ‘bewildered’ in meetings</b> contributor, who, it seemed, found meetings <b>difficult</b> . <i>find it difficult to “say something which might imply a <b>criticism of their clinician</b>”</i>	

## Studies included in the sample

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