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

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)	**comoderating**, **reporting** back or becoming **coauthors**
		Involve partners **right from the star**t
		Provide **background information** in **understandable** language
		Treat all team members **equally**
		promote **open dialogue**
	(m)	**scientific integrity** was maintained when the community had more ownership and participation
		open **communication**

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

	(s)	In three projects patient **research partners were engaged in the research team**
		along-the-way **trust** was build up among a vast group of patients who became **owners of the agenda.**
		inclusion of patient representatives in programme committees.
		a **broader definition of the agenda** created more opportunities for multidisciplinary collaboration
		Patient organizations and researchers can also act as ambassadors and lobby for certain topics.
		Open attitude towards
		Willingness towards
		Adequate **resources**
		Expertise
		Collaboration between fund and patient organization with middle and long-term goals
		Appoint **policy maker** for inclusion patient perspective
		appoint **patient representative** to work with fund
		Include patient representatives in program **committee**
		identify **priorities** based on research **agenda**
		Organize **pool of patient research partners**
	(v)	someone with **credibility**, and they need to say which organization they represent
	(y)	**Trust**
		Aboriginal staff and clients were more **willing to accept anecdotal data** (eg, stories) on 'face value'.
		relationship with the local community
		culturally appropriate research materials
		staff they knew and trusted
Barriers	(f)	community members whose participation was initially more **passive** or **tokenistic**
		pressure to maintain **funding** to ''keep the doors open''
		Participation, although initially high, dwindled until during the final days when no youth participated
	(o)	*no one ever asks the people*
	(p)	He [the researcher] has **terrific people skills**
		"How many sexual partners have you had in your entire life?" It was **intrusive,** and our staff didn't like it
	(r)	PPE methods were often described as either **tokenistic** (e.g. consultation or audit)
		stigma
		ethnic/religious barriers limit LBGT involvement
		patients have **other commitments**
		more urgent needs
		I think most people who are ill just want to get better, they don't want to get political…
	(s)	*the fact that you do not have* **enough** *people [to carry out those plans]*
		enthusiastic, but did not know what to expect and what aspects required specific attention.
	(t)	**apprehensive** about working with researchers
		distrustful of future interactions with researchers.
		lack of understanding of study participants' needs
		feeling of discomfort
		There is no real quid pro quo *in the relationship between academic centres and community people.*
	(v)	people need to feel like their privacy is not being threatened.
		It takes a while to build trust,
	(y)	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

Design and recruitment phase		
Facil	(q)	flexibility
	(x)	**Specify patients' role** so that they feel more competent and **prevent false expectations**
Barriers	(c)	desire to limit contact **with government authorities**
		punitive policy and **legal environments**
	(d)	**difficulty in determining their experience**s (…) **hesitated** (…) changed their answer
	(i)	The research questions elicited numerous '**sensitive' disclosure**
	(q)	some less able to **articulate their views**
		some wanting to do **something impossible**
		lack of **confidence** about contributing at meetings
		not realising how much **training** the panel might need
		Jargon
Engagement and co-production phases		
Facilitators	(i)	ethical, respectful process.
		Care in word choice
		time to recall and represent their experiences in an unhurried manner
		the writing enabling a reflective process (…) **without having to manage emotions**.
		anonymity *so you can be perhaps a bit more forthright/honest than face to face*
	(l)	Respect of confidentiality
		Sensitivity to patient value
		structural involvement, the relationship between partners and researchers has developed into equal collaboration

		Participants have tended to **raise the level of competencies required**
		feel **confident enough** to say something
		could all **interact and see each other**
		Especially for somebody like me with a hearing **disability** it is important to see all the faces'.
		Tailor support to the competencies of the partners ‣ Provide lay summaries ‣ Create a learning environment: provide training opportunities ‣ Distribute reading materials before meetings ‣ Explain jargon without being asked ‣ Provide glossaries, journals and websites ‣ Help partners access and judge scientific literature
		Be alert for sensitive issues ‣ Partners want to be regarded as individuals, from a holistic perspective ‣ Try to be inclusive ‣ Respect confidentiality and apply ethical rules ‣ Acknowledge contributions
	(r)	Training for patients to prepare them for involvement
	(u)	**mutual respect** and **acknowledgement** between service users and providers.
		be to **be heard, seen, and valued.**
	(x)	give them a sense **of responsibility for the decisions and increase their participation**
		Value the patients' perspective and their participation, give them feedback
	(c)	**rapport**
		meaningful relationships with research 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 **manage emotions**.
		*I didn't have **body language interfering** like it can sometimes…or have **anyone interrupting** me*
		intrusiveness of body language
		potential **disruptiveness** of the interviewer to her train of thought
	(k)	*The only thing that we've got to bring to it (is) our own experiences*
	(l)	Intensity of the programme
		Physically challenging
		Accessibility
		Mentally challenging
		Language and terminology
		tokenism
		Scepticism (..) **Imperceptibility of contributions**
		felt **ignored**, **frustrated** or **unable** to contribute.
		language was also a barrier for some whose first language is not English.
		Moderators' behaviour was sometimes considered **unethical** or to be a **poor approach to sensitive issues**.
		Not involved from the beginning
		Lack of information
		Power imbalance
	(q)	lack of **engagement**
		just being **confident enough to make your point**
		not knowing what was expected of them and of feeling 'bewildered' in meetings
		contributor, who, it seemed, found meetings **difficult**.
		*find it difficult to "say something which might imply a **criticism of their clinician"***
	(x)	medical and scientific jargon
		false expectations
		Lack of familiarity with the scientific language
		abbreviations and very scientific terms
		Patient representatives indicated that all too often they were consulted without receiving any feedback on their contribution.

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