

Consumer engagement to improve health care: facilitators and barriers^a

<i>Design of engagement</i>	
Facilitators	Barriers
Enhancing consumer/carer input	
<ul style="list-style-type: none"> • Enable consumers or carers to set the agenda • Enable consumers or carers to participate in all/most stages of the research (participatory action research) • Include more consumers than providers to enhance consumer voice • Offer flexibility in levels of and approaches to involvement • Build in reward mechanisms such as feedback and evaluation • Set opportunities for regular and frequent opportunities for interaction 	<ul style="list-style-type: none"> • Overly complex discussions • Onerous, time-intensive involvement • Including a disproportionate number of consumers to providers • Including providers who have cared for the consumers involved • Including groups of people with existing hierarchical structures
Creating a receptive context	
<ul style="list-style-type: none"> • Use a democratic dialogue to build consensus • Use external, trained facilitators • Conduct training sessions before engagements to clarify roles and objectives, develop skills, increase sensitivity to cultural or community issues and reduce power imbalances • Maintain flexibility in aims, design and outcomes in response to consumers' input • Enable time to develop strong and trusting relationships • Create an environment where participants are able to communicate in their preferred language 	<ul style="list-style-type: none"> • Lack of clarity on: <ul style="list-style-type: none"> – roles – objectives – responsibilities
Leadership actions	
<ul style="list-style-type: none"> • Secure institutional commitment and sponsorship for engagement • Involve institutional leadership • Engage consumers before decisions have been made • Establish mechanisms to act on issues raised and to continue involvement • Demonstrate progress between meetings 	<ul style="list-style-type: none"> • Engagements conducted by consultative groups, not decision-makers • Lack of response to or plans to address issues raised • Lack of follow-up with consumers after their participation • Policies and procedures misaligned with participation, recommendations or outcomes

Sampling participants	
Facilitators	Barriers
Enhancing patient/carer input	
<ul style="list-style-type: none"> • Consumers conduct interviews with fellow consumers, when possible • Have a wide representation of consumers at all stages • Identify and recruit users through providers, existing users, networks • Offer incentives (monetary and other), stipends, reimbursement of expenses 	<ul style="list-style-type: none"> • Provider- or consumer-led recruitment can introduce biases • Including self-selected participants (eg, confident consumers or those with fewer symptoms or family care duties) • Inclusion of proxy groups (eg, parents representing children; carers representing consumers) • Ethical concerns about recruitment of and consent from consumers with intellectual or physical disabilities
Creating a receptive context	
<ul style="list-style-type: none"> • Consider setting: engage consumers at home, in their facilities or in environments outside where services are delivered to increase participation and comfort 	<ul style="list-style-type: none"> • Lack of participant commitment • Lack of participant confidence • Providers who are sceptical of involving consumers • Providers who feel threatened by devolving power • Providers whose behaviour does not promote user participation
Leadership actions	
<ul style="list-style-type: none"> • Emphasise to consumers the organisational commitment to/ sponsorship of the engagement with consumers 	

^a Adapted from Bombard Y, Baker GR, Orlando E, et al. 2018. Engaging patients to improve quality of care: a systematic review. *Implementation Science* 13: 98. DOI: 10.1186/s13012-018-0784-z.

The systematic review that informed this table included 48 studies and aimed to identify the strategies and contextual factors that enable optimal engagement of patients in the design, delivery and evaluation of health services.