Understanding and organising evidence on social power and participation in health systems

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Contents

Executive summary

In 2016/7 work is being implemented to gather evidence on promising practices in and models of authentic community participation, power and decision-making in health systems from selected high, middle and low income countries; to identify and share learning for adaptation in local or state-wide sites in the USA. This document serves two purposes for the work:

- Firstly, it summarises key concepts used in the literature on social / community participation and power in health systems. It does this to support a shared general understanding of and a 'common language' on the different dimensions of social participation in health systems for exchanges across different settings in the project; and
- Secondly, it sets a generic framework, from which more specific, focused templates/ frameworks will be drawn to gather evidence in the literature review; and the US site briefs and country case studies.

Drawing on published literature, the document summarises, for the first purpose, definitions of key terms, the conceptual framing of key dimensions of social/community participation and power as relevant to local health systems, and to cross sectoral collaborations for improved population health. It points to the multidimensional and dynamic nature, forms and levels of social participation, linked to power, voice and agency within different formal and informal spaces that may be provided or claimed.

A broad framework is presented in Section 4. At the *centre is the analysis of promising local practice,* as an interaction between the nature of the community and other actors; the dimensions of the health system involved; and the nature of participation and the social power generated. It aims to guide a rich description of the local level, an understanding of the positive and negative feedback loops between the different elements and how they link to the intended and realised *social, system, process and health changes and outcomes.* It locates the local level within the *wider contextual conditions* affecting it, and the *meso-level measures and mechanisms* enabling, supporting, and sustaining it, as they affect the three central elements, and the interactions between them. These elements are summarised below.

Key elements of the framework

The context for participation:
1. Relevant normative, socio-political, economic, governance and health system context

The nature of community / actors:
2. How the community role is understood in health (as citizen, beneficiary or consumer), and the level of engagement from individual to family, to social group, community and wider public and social levels.
3. The features of the social group involved; their interests in and capacities for social participation; and the mandate/ legitimacy/ voice and capacity of community representatives.
4. The contribution of a range of other visible and invisible actors.

The dimensions of the health system:
5. The dimensions of health system functioning and decision making involved (information; needs assessment; planning; policy deliberation; health actions, oversight), and interactions with other sectors.

The nature of participation and power:
6. The different levels and forms of participation, and whether externally induced /organic; invited/ claimed, and the interests and motivations of system and community actors.
7. The goals and scope of participation, and whether focused on social features, issues or diseases;
8. The nature and organisation of the opportunities, spaces, mechanisms, processes, methods, and tools for participation, formal / informal, sustained/ temporary; who accesses them and how they are used.
9. The forms and levels of power exercised by community and system actors; including in decision making.

Cross cutting issues:
10. The strategies, processes, resources, tools and capabilities supporting local participation; the enablers and barriers; and the social, health, and health system outcomes.

(Interactions shown diagrammatically in *Figure 4* on p23 and a more detailed outline in *Box 4* on p20).

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1. Background

Health systems face challenges in ensuring universal access, in reaching and appropriately caring for socioeconomically and culturally diverse communities, in engaging other sectors around the social determinants of health (SDH) and in tapping opportunities for and meeting emergent challenges to health, including from changes in society and people's exposure to a wide range of social media. International evidence indicates that meeting these challenges and addressing health disparities calls in part for a health system, particularly at primary care level, that is proactive, oriented to communities, families and individuals, comprehensive, participatory and linked with other services and activities that improve population health (Gilson et al., 2008).

Increasing social literacy and a growing recognition that people's values, preferences, and lifestyles ought to be incorporated into the decision-making process when assessing the merits of various treatment alternatives for specific health problems is motivating attention to social participation in health (Charles and DeMaio 1993; Mooney et al., 2007). This calls for 'people-centred' health systems and 'a culture of health', in which people are involved as members of communities in health promotion and in fair policy making on services, and not only as individual passive patients seeking treatment for ill health in services shaped by others (WHO 2008; Matheson 2012).

This means that systems need to involve people in deciding, acting on and contributing to improvements in health and wellbeing, and to organise the public information, relationships, leadership and capacities to support this (Gilson et al., 2008). For example, the four action areas on the Robert Wood Johnson Foundation's (RWJF) Culture of Health Action Framework (RWJF 2015) all involve social participation in:
  a. Building shared values in health, such as through public dialogue and engagement;
  b. Investing in community practices and capabilities for health in settings such as schools and workplaces, bringing community roles to 'Cross-Sector collaboration to improve well-being.'
  c. Raising the profile of community needs and building literacy and social inclusion to strengthen 'Healthier, more equitable communities'; and
  d. Bringing active participation, informed engagement, shared decision-making and social accountability in the 'Integration of health services and systems.'

This has raised interest in the conditions, mechanisms, processes and tools used in health systems for authentic participation by autonomous, competent and empowered actors (Cornwall 2008a).

In 2016/17, TARSC is implementing work, with partners, to gather *substantive* evidence on *promising practices in and models* of authentic community participation, power and decision-making in health systems from selected high, middle and low income countries; to identify and share learning for adaptation in local or state-wide sites in the USA. In the *process* of the work, it will connect US sites with those implementing the promising practices in other countries, to build dialogue and networking across institutions and enable ongoing peer to peer exchange and support on approaches and practices that can be adapted locally, in the USA and in other countries.

This document serves two purposes for the work:

- **Firstly, it outlines a summary of the key concepts used in the literature in social / community participation and power on health systems. It does this to support a shared general understanding of and a 'common language' on the different dimensions of social participation in health systems to apply in the exchanges across different settings;**

- **Secondly, it sets a generic framework, from which more specific templates/frameworks will be drawn for organising evidence for the literature review; US site briefs and country case studies (with proposals for the specific frameworks shown in the Appendices for review).**

Drawing on published literature, the document presents evidence on key dimensions of social participation[1] and power as relevant to local health systems, and to cross sectoral collaborations for improved population health and health equity. The focus of this project is explicitly not *whether* to implement social participation and power (as means), but *how* to implement it, what is promising and under what conditions (as an end in itself). This makes selection, investigation of and exchange on promising practice, on 'what works', a key focus of the project, and to some extent this paper. At the same time it is noted that social participation can impose burdens, that people's perceptions differ on how and how far they seek to be involved, and that disempowering conditions and barriers are important to note, including within promising practice.

2.   Methods

A search was implemented of published literature on conceptual/ analytic frameworks on social participation and power in health systems[2]. The searches were implemented in three major online databases, viz: Pubmed/Medline; Google Scholar and SciELO. Searches included documents from 1995 to current in English, Spanish and Portuguese, for any geographical area.

The key word searches were applied to the titles of the papers, to include papers that were focused on elaborating analytic or conceptual frameworks in the area, rather than simply including note of it in the text. In terms of participation/ power, papers were included if they covered patients or communities, and if they referred to one or more dimensions and levels of participation. The abstracts of the papers sourced were reviewed for their relevance to the inclusion criteria, particularly if they elaborated analytic/ conceptual frameworks. Duplicate papers (from another online library) were excluded, as were those that were earlier versions of an included paper by the same authors, where the same concepts were already covered.

Table 1: Papers included in searches

Online Library	# papers included from the title search	# papers included after title/ abstract review
Search 1 for analytic/ conceptual frameworks		
Pubmed/Medline	106	12
Google Scholar	168	13
Scielo	137	20
Sub-total	411	45
Search 2 of systematic reviews		
Pubmed/Medline	307*	14
Google Scholar	46	14
Scielo	74	1
Sub-total	420	29
Total	831	74

(*) Included search of both title and abstract

The full set of 74 papers from the searches was then sourced and read by the first author. On the basis of this further exclusions were made of papers that did not meet inclusion criteria for the development of the analytic/ conceptual framework. Further papers were found from reference lists, from snowballing and from peer reviewer input. A final set of 64 papers was used, shown in the reference list to this document, together with three further cited in the introduction.

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[1] The terms social and community are further defined and discussed in Section 3.2. Given the project's local and population health focus, it mainly (but not exclusively) focuses on 'community' participation. The term 'social' participation is used cover more generic reference to participation from individual to family, community and wider levels,

[2] The search for papers used as key words 'conceptual framework' OR 'analytic framework' AND 'participation' OR 'power' AND 'health' OR 'healthcare' OR 'services'. A second search was implemented using as key words 'systematic review' AND 'participation' OR 'power' AND 'health' OR 'healthcare' OR 'services' to identify the analytic frameworks used in these systematic reviews. A health system, also sometimes referred to as health care system or healthcare system, is understood to be the organization of people, institutions, and resources that deliver health services and undertake activities whose primary purpose is to promote, restore, and maintain health.

There are some limitations in the methods and the materials sourced. Grey literature was not included, although the papers included indicated that there was saturation of new information on key analytic concepts from those included. Further papers in languages other than English, Spanish and Portuguese may bring new analytic concepts. The first draft of the framework was however sufficiently robust to guide the literature search and annotated bibliography of promising practices on social power and participation in health systems in countries. This draft of the paper has been revised after review feedback by international reviewers in the policy advisory group and has been used to propose the template for briefs on current practices, challenges and desired areas of learning in the US sites. It will be further reviewed as relevant evidence and insights are raised in further work implemented in the project.

As a further caution, Rifkin et al., (2000p.x) in a literature review on participation notes that "the historical development of participatory approaches has been flexible, accommodating, creative and exploratory", commenting that this makes it not possible to give a universal definition of either 'community' or 'participation', and that these concepts depend on the environment in which they exist. The framework generated from the analysis in this paper is thus explicitly generic, and will be applied, revised, extracted from as relevant for the specific purposes of different areas of work in the project.

3.   Findings

This section presents and discusses, albeit briefly, the key concepts applied in work on social participation and power in health systems. Section 4 explores how they interact and can be integrated in a multi-dimensional framework. This section examines in particular the understanding and key features of context and community; the dimensions and levels of power and participation in health systems; and their impact on health, as key issues for the project.

3.1: Understanding context

Numerous papers raise the need to understand how context, history, and culture shape the norms, values, conditions for and the nature of participation and social power. While there may be additional unique contextual features in different countries, across many papers the features that were commonly seen to have influence on social power and participation in health included:
- *Socio-political and institutional beliefs, norms and values* within society and its subgroups and within the health system, including the extent to which and spheres in which they invoke solidarity, collective action, social inclusion, non-discrimination, equity and social justice.
- The history and evolution of the *state and government and the ideologies and political culture*, including the relationships of power, hegemony / subordination and the cultural and political rights, constitutional, legal and policy frameworks and social organisations that maintain these relations, and the extent to which they support an active civic culture and democratic systems.
- The *material and economic conditions*, social groups and levels of multiculturalism, of social (in)equality and the burden and distribution of ill health.
- The *population health orientation of the health system*; its design to achieve outreach to/ coverage of communities for promotion, prevention and care, and its level of collaboration/ integration with other sectors affecting health (Gonzalez 2015; Mittler et al., 2013; WHO 2010).

These features influence the activities and spaces available to and used by different social groups and the differentials in power, capacities, material and social resources available for these actions (Arenas-Monreal et al., 2015). There may be a mix of conditions, norms, cultures, groups, features and systems within countries, settings and even within households. For example in Colombia, Gonzalez describes distinct and different health system contexts and models for indigenous people that co-exist within the same setting with the prevailing biomedical system, with varying levels of dialogue, sharing of knowledge and collaboration across these distinct systems (Gonzalez 2015).

3.2: Defining community, power and participation

Who participates?

The public invoked can be universal (referring to people or citizens) or highly specific, geographically located communities. *Community* is a widely used term to describe people living and interacting in particular geographical locations or with common /shared interests, identity, goals or occupation. It can be used to refer to people living in the geographical/ catchment area of a specific health centre. The term *social* is used to refer to society and its organisation, at a wide level, and in this paper is used descriptively to cover the generic inclusion of all levels of society, individuals, family, community and the general public. A range of terms in the literature describe the public in its interface with the health system (See *Box 1* below),

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Box 1: Terms used to denote members of communities

The terms used to denote community reflect to some extent the paradigm of participation invoked, discussed later. All three terms below can be differentiated from the use of *patients*, as they all include also those who are healthy and the promotion of health:

- **Lay person,** considered by some to be an outdated term, is usually used to denote someone not directly employed in the system or without professional qualifications who participates in a health committee or process in the system, albeit without a specific constituency;

- **Consumer** is a term used by consumer health organisations as a more active term than 'patient', referring to people who use, are affected by, or who are entitled or compelled to use health care services. Some countries refer to 'beneficiaries', as members of health insurance benefit schemes. Consumers are envisaged to make rational decisions in health care and to promote co-determination in services. It is noted by some to imply a relationship with market goods that does not apply to health services that are often provided publicly and outside the market. A *consumer representative* is a person - usually but not always selected by a members of a consumer organisation - who voices the consumer perspective and takes part in the decision-making process on behalf of consumers.

- **Citizen** is used to denote members of the public in their relationship to the state, nation or other political entity. It implies a right to participation; agency in those who participate; and status, responsibility and the ability to have a say for the specific social group, but also for society as a whole. Citizens can be presented as consumers in relation to their *individual* (health) rights and entitlements as consumers; but also as members of a community with *social* rights and responsibilities, in an interface with governance institutions and multiple forms of solidarity. Citizenship is an active term, suggesting an awareness of rights, legal and institutional procedures, a disposition toward action, and capacities to exercise rights, participate in democratic life and hold the state to account. Citizens organise socially in *civil society, civic networks and associations*, some general and some around particular issues of concern, engaging in processes that determine the affairs of their community and their lives.

Sources: Benequista et al., 2010; Coney 2004; Cornwall and Leach 2010; Coulter 2009; Newbury and Wallace 2014, MacDonald et al., 2007.

People participate from **individual to social level**. They are involved as patients and family members (or wards, especially for children), and may be empowered or disempowered to varying degrees in their 'one on one' relationships within health systems. This may be due to system or social capabilities and features. People may also participate as citizens, individually and as members and representatives of community level organisations and social groups at different levels, with a role in informing, and in decision making and oversight of the health system (Schmidt et al., 2009). As further discussed in later sections, information technology and social media are playing an increasing a role in the relationship between people and the health system, with potential benefit in more informed and connected individuals and providers, but also with potential harm from miscommunication and exposure to risk (Lutz et al., 2014; Kruse et al., 2015).

People may grouped by their roles. For example, 'carers' in the community may be family members, friends or local workers. When organised, such social groups gather and share values, attitudes, beliefs and information and bring possible benefit to individuals in terms of access to information, social support and material resources. A group's influence on its individual members and strength is likely to be greater if its members identify with, are attached to, and embedded in the group; if the group has a strong identity; and a high level of cohesiveness and interdependence (Mittler et al., 2013).

Beyond *who* is involved, discussions on participation also explore the extent of **inclusion** and **level of representation.** In relation to inclusion, there are debates about how far all concerned social groups are effectively included in processes, given diverse experience, interests, voice and agency. Some papers indicate that involvement is more common in more economically secure people with pre-existing capacities to organize (Katz et al., 2015). Stigma and discrimination may impede inclusion as may disadvantage due to various dimensions of social and economic marginalisation. Representation is affected by how representatives come forward, who they speak for, who they are seen as speaking for, and the extent to which they are indeed able to speak up, out and for others. The concept of **voice** – the expression of preferences, opinions and views- is used to communicate the autonomy and organisation of those involved, including their capability to communicate views, be heard and to influence (Coney 2004; Street et al., 2013). While these factors may not necessarily result in changes in power, they can contribute to it.

Even where communities play strong roles, **other actors** also play a role: Change usually involves complex coalitions that link communities to formal non state organisations (NGOs), media, intellectuals, activists and others, in a range of networks. The state may be a target of action, but state actors also play a role in opening and closing opportunities for engagement, in championing and sustaining reforms, and in protecting (or contesting) the legitimacy and safety of social organisations and movements. Mediators and brokers at varying degrees of visibility can play a role in bridging groups, whether to frame social demands or to broker dialogue on conflicting positions or between different actors and levels (Benequista et al., 2010; Barr 2012; Paiva et al., 2014).

With what concept of participation?

While the notion of community participation and 'consumer voice' in the health sector is increasingly being mainstreamed, it is not always understood in the same way across countries and actors (Rifkin 2000). Broadly speaking, participation has been described as:

- A process of involving people (individually and collectively) in decision-making about their own health care, and in planning and monitoring services, setting priorities and developing policies;
- An autonomous process of community action in which specific groups with shared needs and interests, sometimes living in a defined geographical area, actively identify their needs, take decisions and establish mechanisms to meet them.
- A process whereby people exercise their right to health, including to play an active and direct role in the development of appropriate health services, in ensuring the conditions for sustained better health and in supporting the empowerment of communities for better health development (Coney 2004).

However, there are differences in how different authors conceptualise participation. In a relatively depoliticized concept, social groups take on a social deficit, with minimal control over policies affecting structural determinants, but with responsibilities for implementation of compensatory actions. This may involve the public as consumers, or as volunteers in an outreach of the current system. It may also imply limited change in current norms, processes and mechanisms, and while people may be hold services accountable on their performance, they may not have powers in areas of decision-making that shape or transform systems and may as volunteers take on unpaid burdens of care (Schütz et al., 2005).

In contrast, some papers articulate a more politicised concept, in which citizens, including as health activists or in social movements, pursue rights and justice, raising collective demands for change in areas of power, discrimination, beliefs, policies and practices that are perceived as inequitable or to limit wellbeing. This includes movements focused on access to services, on health of different social constituencies; or on a specific disease experience (Cornwall and Leach 2010). In some cases this is associated with a rights-based approach to health. In locating people's wellbeing at the centre of a health system, this approach integrates people's right to active and informed participation in the development of health policy, implementation of health actions and in oversight for accountability (Potts 2008).

These debates on the understanding of participation, discussed in subsequent sections, are directly linked to matters of power and control (Rifkin 2001). **Power** is understood as 'the capacity to make a difference, to transform something from one state to another', either as an individual action or as an outcome of a larger system. Power is proposed to take four different forms:
- *Power over* - referring to domination, control and repression, controlling action.
- *Power within* - referring to the internal capacity, self-confidence, self-worth and self-consciousness that people have that support self-determined thinking and action;
- *Power to* - referring to the ability to take action to influence the world, and
- '*Power with*' referring to the power created through collective action, where the whole is greater than the sum of the individuals (Spencer 2014; Coney 2004; Sanabria and Balcalzar 2005).

These four forms may be expressed by different actors (in the community, professionals and managers) and institutions (companies, public services) and in different types (such as political, social, technical power). Whatever type and actor, e**mpowerment** is understood as the *self-developed* growth in that capacity to make a difference, to control and transform, whether within individuals or collectively. Power is affected by self-perception, such as the beliefs and assumptions people have about the control they have over their health and its determinants (Sanabira and Balcalzar 2005). Empowerment is thus a 'bottom-up' process, developed and gained by people themselves, rather than granted by others. The term '*authentic*', when used in this context, can be read to reflect this 'bottom up' self-claimed power, with a growth in self-esteem and self-efficacy, collective consciousness and capabilities to decide, act on, control and produce changes in people's own conditions. As discussed in the next section, participation on its own does not equate to such a growth in power, and may not necessarily enable people to exercise power in key decisions or in control over resources that affect their wellbeing.

3.3: Participation in diverse dimensions of health systems

As noted earlier, the nature, drivers and motivations for participation in health systems could be both political and/or pragmatic in nature. Social participation has been integrated as a demand side 'intervention', to address barriers to access and acceptability of services and as a means to involve people as active participants in their own health care (Mittler et al., 2013). Community members are involved as partners in health care by generating their own ideas, assessing their needs, being involved in decision-making, planning, implementing, and evaluating the care they receive. In a pragmatic view, participation is seen to contribute to the functioning of health systems. George et al., (2015) found in one systematic review, for example, that community participation was integrated in various functions of health systems, including: (1) health promotion, (2) inter-sectoral action, (3) service delivery, (4) governance, (5) supply chain management, (6) financing, (7) human resource management and in (8) information systems. The community roles varied in how they viewed health; and in their scale, duration, influence and balance in relation to professional roles.

Participation is, however, also identified to have become more prominent as a result of political drivers, including popular movements that have generated demand and sometimes conflict around health determinants and around co-determination, within wider processes of decentralization and local autonomy (Amar Amar and Molna 2008). This view locates individuals, families and communities in a more powerful position as decision makers and as agents of change, including change in the health system. Popular demands have, for example, often been directed at root causes of disease and inequities in health,

engaging health and other sectors to act on these social determinants (Camargo and Pinzon Villate 2012). Such processes can confront vertical disease and professional discourses that dominate and depress the community's own understanding of health and disease (Heidemann et al., 2010). Within a rights based approach, it involves institutional change to provide information and mechanisms for people to participate in agenda setting, in policy development, priority setting, and appropriate service delivery, to ensure that people have the freedom to make decisions about their health and to hold the state accountable for its obligations (Potts 2008). In these cases beyond the functions and areas of participation, the *process* is given attention for its contribution to empowerment. Hence, for example, participatory processes can be scrutinised for how far they build collective understanding and confidence to act, such as by collectively validating people's *own* experience, facilitating shared dialogue on problems, their causes and possible actions, and reviewing learning from action (Heidemann et al., 2010; Loewenson et al., 2014).

This section outlines further the ***key dimensions of health system functioning*** within which social power and participation is expressed. The next explores further *the **nature of the processes within which participation is organised, and how far they shift power and control to communities.***

This project focuses on the local level of health systems, particularly in their role in advancing population health, including in the arrangements and measures for health promotion, prevention, public health and intersectoral co-ordination between health and other sectors to address key social determinants of health. This implies understanding where decisions are taken and where control over resources, action and oversight locates within these different functions. Comprehensive reviews of health system functioning, and particularly of functions that address population health, health equity and effective primary care point to six areas of health system functioning within which to explore how social power and participation are organised (Gilson et al., 2008; Loewenson and Gilson 2012; Loewenson et al., 2014b; Cornwall 2008; Coulter 2009). These are:

1. Community health literacy, public information and the use of community knowledge on health.
2. Assessment, identification and prioritization of health needs.
3. Health planning and decision making on spending priorities, resources and budgets.
4. Policy deliberation and formulating strategic policy direction.
5. Co-design, co-ordination and co-production/ implementation of health actions, and
6. Oversight, monitoring, evaluation, review and improvement of services/actions/quality including measures of social outcomes.

The internet and social media are increasingly playing a role in many of these areas, with potential for benefit and harm. It has, for example, been used in patient portals, as a vehicle for health information and for individuals to better understand their own health and treatment issues (although with potential also for spread of inaccurate information), and to support participatory tools for needs assessment, to draw preferences and improve the transparency of decision making, share capacities and experience of practice. It has been used for support and exchange, including by people who are otherwise socially isolated or stigmatised (Lutz et al., 2014; Kruse et al., 2015).

Each of the six areas is further discussed below:

1. **Community health literacy, public information and the use of community knowledge on health.** This includes facilitating information flows and communication between providers and community, directly or indirectly, such as through online platforms, and involvement in promoting health and health literacy in communities. While health promotion is argued to be inherently democratic and participatory in nature, supporting people to gain control of their health (Carlisle 2000), it can also be implemented in ways that shift burdens to communities and keep decision-making at higher or technical levels. There is thus a question of how far information and promotion activities not only use what is defined by 'experts',

but also experiential expertise, perspectives and collective proposals from communities (Cornwall and Leach 2010; Loewenson et al., 2014a).

2. **People participate in the assessment, identification and prioritization of health needs,** in
   - Registering / enrolling catchment populations/ groups/ families and individuals into services;
   - Generating intelligence for stewardship of systems;
   - Mapping population and family health needs, including through participatory approaches;
   - Consultations with communities on health needs and priorities; and in
   - Carrying out specific areas of population health research.

Wilson and Lavis (2014) found communities involved in a number of areas of priority setting, viz:
In generating evidence and identifying priorities in health-system arrangements, implementation strategies, programmes and services, and in relation to medicines. Processes that validate the experience of those directly affected by health issues can overcome the disempowerment communities experience when technical debates negate their knowledge and evidence is as less relevant opinions and views, or even as ignorance (Cornwall and Leach 2010). Various ways of integrating community experience and inputs are documented, including: participatory processes of family mapping involving local health teams; and visual methods of mapping, ranking and scoring that generate a collective view that is checked, verified, amended, added to, and owned by the participants (Loewenson et al., 2014).

3. **Communities may be involved in health planning and decision making on spending priorities, resources and budgets.** This may be done in deliberative forums and processes that choose between different service options; in participatory budgeting; or in decisions on human resource development and management. Citizen engagement in co-determining health plans and budgets is important, given the finite and often scarce resources. It is a terrain of engagement between potentially conflicting interests that is affected by the rules, principles and processes that shape decision making (Hufty 2010). Mooney et al, (2014) argue the complex and technical nature of health care decisions means that community preferences are more easily integrated in areas where information can be provided at not too high a cost and where communities themselves have a preference for being involved. Further, while various organizational mechanisms, forums for and deliberations on health planning and budgeting are reported, public funders are also reported to be more cautious about participation in resource allocation, viewing it as weakening rational or equitable financing. The tools for it are thus noted to be relatively under-developed (Moreira and Veiga 2010). As in the previous area, the design of and processes in these 'invited spaces' for co-determination also matter. Citizens are more likely to be forthcoming with their views if they have been able to shape the 'rules of the conversation', that is if they are given sufficient ability, resources and opportunity to define the terms under which they participate, the issues they want to address and to influence the nature of the deliberation (Benequista et al., 2010). Other authors also note that formal spaces are also only part of the story on decision making, and that engagement takes place in other times, spaces and processes, in a plurality of sites. This 'backstage' action in informal spaces may be critical for influencing the agendas, decisions and processes that take place within formal spaces (Cornwall and Leach 2010). This raises the question of where decision making is actually located, and how far communities access, and have capabilities, voice and power within these spaces.

4. **Participation in policy deliberation and formulating strategic policy direction** takes place
   - through deliberative and opinion polling; citizen panels, juries and social consultation mechanisms;
   - on design of services, benefit packages; and resourcing and organisation of services;
   - with measures for integrating social norms and preferences to align policy objectives to social and organizational values, structure and culture; and
   - with measures to map stakeholders and analyse the political economy context for policy changes.

Policy processes do not happen in a vacuum, but within a framework of contesting interests, motivations and incentives, that may be expressed or implicit. The governance of health systems integrates both formal and non-formal processes, including for expressing and resolving conflicting views and interests. As raised in prior areas, these processes are affected by differentials in power and capabilities, by

alliances and resources (Flores 2010; Cornwall and Leach 2010), and by the political freedom that groups have to exercise influence (Carlisle 2000). Participation in policy processes is reported to be undermined by insufficient time given, or when the deliberations are ignored in final policies (Street et al., 2013). Policy engagements in health systems and the role given to participation can be analysed in terms of the policy content, actors and interests involved, and their (different) utilitarian / pragmatic and political motivations for participation. Here to there is need to better understand where decisions are actually being made and policy agreements concluded (Hufty 2010). These are often complex processes: Policy deliberation involves a convergence of different formal and informal spaces in which agendas and norms are set, policy interactions forged, policies developed, discussed and selected and policy implementation and monitoring measures aligned, all of which need to be understood and to better locate the role of social participation and power in this area. This becomes even more challenging when policy deliberation takes place beyond local levels, and in some cases at international level, restricting the space of what can be achieved locally or even nationally.

5. **Participation in co-design, co-ordination and co-production/ implementation of health actions** takes place in:
   - *Treatment services*, to know client and community preferences, to support information exchange, including on medicines, in the exchange on treatment preferences and patient choices and how these affect physician/ health worker behaviour (Charles et al.,1997; Stevenson et al., 2004).
   - The range of community personnel, including *community health workers*, health champions, patient navigators, integrating socio-cultural features and fair compensation (Harun et al., 2013).
   - Commissioning additional services and setting service measures for *quality of interaction*.
   - *Work with other sectors and settings* contributing to SDH, including with schools and workplaces.
   - *Continuity of and access to information*, such as lifetime electronic records or service reports, and in
   - Preventing and responding to *emergencies and disasters*.

While many diverse forms are reported of health action by communities, this may often involve implementing actions decided by others. In contrast, communities may have more power and involvement in shaping these actions, contributing to changes in service orientation and models and in the attitudes and competencies of health personnel, to include features such as:
   i. A holistic 'biopsychosocial' perspective, where health and disorders are outcomes of the interaction between levels of biological, psychological and social wellbeing.
   ii. A comprehensive primary health care approach, that builds participation and trust within integrated and intersectoral actions on population health and SDH (Axelsson and Axelsson 2006).
   iii. The patient as person - as an experiencing individual rather than the object of some disease entity.
   iv. Sharing power and responsibility: in egalitarian relationships, recognising patient/ community needs and preferences, encouraging them to voice ideas, in a more symmetrical relationship.
   v. Greater recognition for the therapeutic alliance, relationships and communication between health workers and clients / communities that also recognises the subjectivity of health workers (Mead and Bower 2000; Angel and Frederiksen 2015; Stevenson et al., 2004).

6. **Participation in oversight, monitoring, evaluation, review and improvement of services/actions and measures of outcomes** to:
   - Ensure financial, performance and political accountability, including tracking use of resources; control of corruption, and to build public trust in and legitimacy of health systems;
   - Monitor enforcement of law and regulation and for oversight of contracts;
   - Engage on quality and client satisfaction, including through score cards and public reporting on quality and costs (James et al., 2012); focus groups on care improvement, and using health information and IT to support client access to/ control of their own electronic medical records (EMRs); and use of information to assess quality, equity and other service outcomes; and
   - Through health watches, community councils and participatory research to monitor the health system responsiveness to social concerns and performance against goals and commitments.

Processes for accountability often work through consumer representatives and advisory structures. Molyneux et al., (2012) report that accountability mechanisms commonly involve committees of different types (such as health centre and clinic committees or village / neighbourhood health committees); community groups, patients' rights charters, citizen report cards, suggestion boxes and health clubs. Whatever the mechanism, these processes, as for others, are affected by how they are perceived, function, and by the mandate and strength of communication between representatives and communities. This is noted to not always be in place, due to barriers in both the system and community (Coney 2004). The internet provides new opportunities for these oversight and accountability processes, for communities to report, comment on and contribute to service performance and to self-organise around this, with possibilities of including this input into decision making. There is some evidence that such processes can lead to increased identification, loyalty and satisfaction with services (Coney 2004; Lutz et al., 2014). It depends however on who accesses and uses it.

Overall, all these forms of participation go beyond ad hoc mechanisms and events. They demand social competencies in health workers and imply a range of potential forms, processes and mechanisms for participation, across formal and informal spaces and across different dimensions of systems. The evidence suggests that social participation is more commonly found in information, needs assessment and oversight areas of system functioning, and is less common, or more complex, in areas of planning, budgeting and policy development. These may be areas that relate more directly to decision making, and thus to where power is located in the health system. Even within these areas there is need to better understand exactly where decisions are made, and who is involved in this. This is discussed further in *Section 4.*

Beyond the various functional dimensions of health systems within which people engage, there is also a question of the quality and level of participation, the interests of both the community and the system that are driving – or blocking- it, and the extent to which it is externally induced, or self-driven by the communities. This is discussed in the next section.

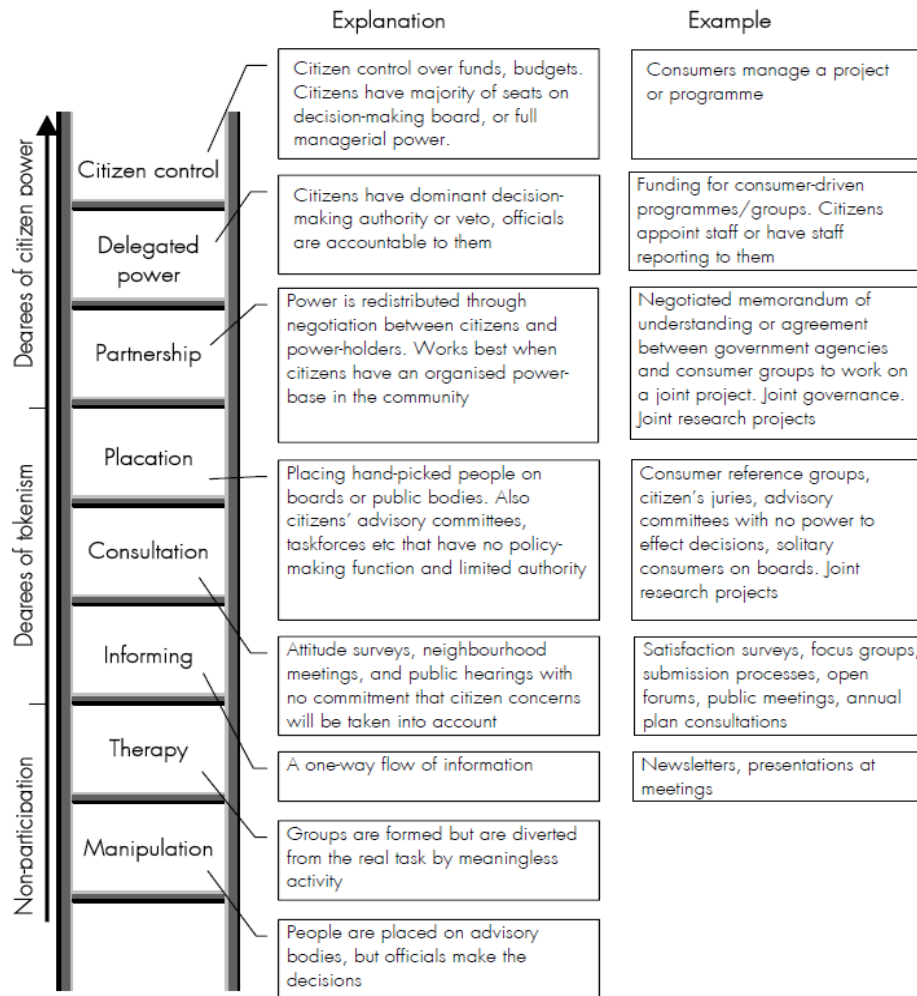## 3.4: Levels and quality of social power and participation

There are a wealth of explanations and 'models' of 'participation': Karsten (2012 np) identifies 36 models and explanations in an "an updated chase through the maze of participation models, frameworks and theories". Many are variations of similar models. This section refers to those approaches that add new dimensions to understanding how participation is exercised in health systems.

Many models categorise the **different levels** of participation and power, associating this with different forms of participation: These range from low levels in manipulation, informing, through to consultation, to partnership and delegated power through to co-determination and citizen control. Participation without a redistribution of power has been criticized as hollow and tokenist so that the model implies a move towards those forms of participation in which public actors and communities play a role co-determining, controlling or co-producing interventions and health outcomes (Arnstein 1962;Vega-Romero and Torres-Tovar 2011).

In her ladder of citizen participation, Arnstein (1969) argues that *citizen participation involves a redistribution of power, so that those who previously didn't have it, share it to enable significant social reform and a more equal society, in a context of divergent groups and viewpoints* (p 216) (see *Figure 1*). This typology, similar to others cited in Karsten (2012), Coney (2004) and Dickinson and Prabhakar (2009), describes the levels of control over processes by citizens. It has been used to characterise levels of participation in terms of the control they imply over processes and to assess whether a shift in these levels take place. In some approaches it is complemented by identification of the openings, opportunities and obligations for these different levels of participation (such as in Shier's Pathways to participation cited in Karsten 2012).In others the levels are aligned to particular spheres of participation, such as from consumer, to commentator, to contributor to commentator in online communities (Wenmoth cited in Karsten 2012). The IAP2 (2007) align the levels and forms to what is appropriate for the goals, time frames and resources available.

Figure 1: Arnstein's ladder of Citizen participation

	Explanation	Example
Citizen control	Citizen control over funds, budgets. Citizens have majority of seats on decision-making board, or full managerial power.	Consumers manage a project or programme
Delegated power	Citizens have dominant decision-making authority or veto, officials are accountable to them	Funding for consumer-driven programmes/groups. Citizens appoint staff or have staff reporting to them
Partnership	Power is redistributed through negotiation between citizens and power-holders. Works best when citizens have an organised power-base in the community	Negotiated memorandum of understanding or agreement between government agencies and consumer groups to work on a joint project. Joint governance. Joint research projects
Placation / Consultation	Placing hand-picked people on boards or public bodies. Also citizens' advisory committees, taskforces etc that have no policy-making function and limited authority	Consumer reference groups, citizen's juries, advisory committees with no power to effect decisions, solitary consumers on boards. Joint research projects
Informing	Attitude surveys, neighbourhood meetings, and public hearings with no commitment that citizen concerns will be taken into account	Satisfaction surveys, focus groups, submission processes, open forums, public meetings, annual plan consultations
Therapy	A one-way flow of information	Newsletters, presentations at meetings
Manipulation	Groups are formed but are diverted from the real task by meaningless activity	
	People are placed on advisory bodies, but officials make the decisions	

Source: Arnstein 1969 in Coney 2004 p21

Others have moved away from visualising these levels as a ladder, arguing that participation and any shifts in power are neither sequential, nor do they evolve in a progressive hierarchy (Treseder in Karsten 2012). A characterisation by levels is argued to not adequately reflect how wealth and power is (re) distributed in processes, nor **how the participation was induced.** Some 'consumer involvement' initiatives may, for example, involve individual mobilisation and decision making, but in ways that are induced top-down rather than organically from grassroots organisation (Coney 2004). While the right to health may imply that processes for participation give all involved equal opportunity to voice their views and concerns (Potts 2008), voluntary activities may be at significant cost and sometimes burden and risk to those involved. The motivation to participate is thus identified as an important feature. Pretty, in Cornwall (2008), adds, therefore, a typology that clarifies the source and motivations of participatory practices, shown in *Box 2.* In this approach, beyond the forms of participation and levels of control (in Arnstein's ladder) the question is asked how and from whom participation was generated. Self-initiated participation is identified as the deepest category, albeit without any assumption that it challenges existing distributions of wealth and power.

Barr (2012) and and Rodríguez Salvá et al., (2010) explore the motivations further raising more explicitly the interests and benefits that motivate participation. This includes factors such as the expectation of direct or indirect benefits, altruistic motives based on values or ideals; or material benefits (e.g. training, allowances and future jobs). A **typology of interests**, shown in *Table 1* overleaf, distinguishes between the motivations of "participants" and of the "implementing agencies" within four different levels of participation, from nominal through to transformative.

Box 2: Pretty's typology of participation

Manipulative participation	Participation is simply a pretence, with 'people's' representatives on official boards, but who are un-elected and have no power.
Passive participation	People participate by being told what has been decided or has already happened. It involves unilateral announcements of professional information by an administration without listening to people's responses.
Participation by consultation	People participate by being consulted or by answering questions. External agents define problems and information-gathering processes, and control analysis, without conceding any share in decision-making, and professionals are under no obligation to take on board people's views.
Participation for material Incentives	People participate by contributing resources in return for food, cash or other material incentives, without involvement the process of learning, or in prolonging technologies or practices when the incentives end.
Functional participation	Participation is seen by external agencies as a means to achieve project goals, or to reduce costs. People may participate by forming groups to meet predetermined objectives related to the project. Such involvement may be interactive and involve shared decision-making, but tends to arise only after major decisions have already been made by external agents. At worst, local people may be co-opted to serve external goals.
Interactive participation	People participate in joint analysis, development of action plans and formation or strengthening of local institutions. Participation is seen as a right, not just a means to achieve project goals. The process involves interdisciplinary methods that seek multiple perspectives and use of systemic and structured learning processes. As groups take control over local decisions and determine use of available resources, so they have a stake in maintaining structures or practices.
Self-mobilization	People participate by taking initiatives independently of external institutions to change systems. They develop contacts with external institutions for the resources and technical advice they need, but retain control over how resources are used. Self-mobilization can spread if there is an enabling framework of support, but may or may not challenge existing distributions of wealth and power.

Source: Cornwall 2008 p272.

Table 1: White's typology of interests

Form of participation	What 'participation' means to the implementing agency	What 'participation' means to those on the receiving end	What 'participation' is for
Nominal	Legitimation- to show they are doing something	Inclusion- to retain some access to potential benefits	Display
Instrumental	Efficiency- to limit funders input, draw on community contributions and make projects more cost- effective	Cost- of time spent on project labour and other activities	As a means of achieving cost effectiveness and local facilities
Representative	Sustainability- to avoid creating dependency	Leverage- to influence the shape the project takes and its management	To give people a voice in determining their own development
Transformative	Empowerment- to enable people to make their own decisions, work out what to do and take action	Empowerment- to be able to act and decide for themselves	Both as a means and an end; a continuing dynamic

Source: Cornwall 2008 p 273

These different explanatory approaches refer to the different forms and levels of **power,** described earlier. Arnstein's ladder reflects a shift from *power over* towards *power to*. For both Pretty and White, approach, the multi –faceted nature of '*power over'* is argued to potentially lead people to internalise and legitimise their own oppression, in nominal and instrumental forms of participation. In this case the *power to* act and influence may be found in representative forms of participation, where there is greater control. However by giving more attention to where participation was induced and why, they draw attention to the *power within*, and the ideas and information that affect people's consciousness and the self-image and the interests that motivate self-determined action (Newbury and Wallace 2014; Coney 2004; Barr 2012). This means that it is not simply the participation in co-determination or co-production that reflects empowerment, as indicated in the previous section, but also the extent to which this involvement is (or is not) self-determined, induced by own consciousness and interests.

These linear and hierarchical models are argued to fail to capture the **dynamic and changing nature** of people's involvement or agency in different processes and issues and at different times (Oxford Policy Management 2013).

Cornwall (2008) and Gaventa (2006) seek to address this by framing **participation as a spatial practice**, where power, voice and agency interact within different categories of spaces:

• *Closed spaces:* that are hard to enter, where decisions are taken by a specific set of actors behind closed doors, usually in a non-participatory manner.
• *Invited spaces:* created by external agencies (local government and non-state organisations) in which people are invited to participate and the rules are usually framed by those who create them.
• *Claimed/organic spaces:* created by people themselves, often as collective and popular self-organising spaces united around a common cause.

These spaces interface and what happens in one has impact on others. Cornwall further separates out
• *durable* spaces, used for interaction with/in the state through statutory bodies, co-management committees and service user groups or outside the state, where citizens engage in sustained governance work through lobbying and advocacy on various public policy issues, and
• *transient* spaces for interaction with/in the state through one-off meetings, events or temporary exercises aimed at deliberation over policies or services delivery priorities, or for interaction without and on the state in temporary civil society issues based processes (Newbury and Wallace 2014; Cornwall and Leach 2010).

Within these spaces there are issues of
• who created the space and the rules governing entry;
• who accesses the space, how well prepared are they and the barriers to access;
• the purpose and nature of the space;
• who participates in the space and how well they can perform, given the rules (and whether these are empowering and enabling or limiting and obstructive), and
• what enables success (Newbury and Wallace 2014; Luque et al., 2014; González 2015).

The **multiple sites of participation** go beyond the official spaces into which citizens are invited to participate (Cornwall and Leach 2010). While the literature largely focuses on forms of invited participation 'inside' the system, in health, participatory interventions also operate in sites that are familiar to communities, such as markets or barbershops (Luque et al., 2014). Working 'inside' is observed to carry risks of social co-option, unless there is a willingness to forsake good relations and 'go public' when needed. Less well described 'outside–the–system processes are thus equally important, particularly when there are inequities in the mainstream of systems and institutions (Coney 2004). Working 'outside' includes activities such as producing alternative sources of information (such as through newsletters, broadsheets, workshops, meetings) that validate and share experiences within the constituency; linking with others inside the system; cultivating internal allies and providing unique evidence. The internet is again identified as a resource for self-organisation and sharing within social groups (Lutz et al., 2014), although with some debate on which

online activities can be considered "true" participation and which are more symbolic. There is some evidence that even low–threshold forms of online participation, such as information sharing, may be positively connected to more resource–intensive forms, like engaging in a political organization, especially for those at higher education, socio-economic levels and with online skills (Lutze et al., 2014).

These models help to differentiate levels and forms of participation, but have a number of limitations. Firstly they do not explore their **dynamic interaction with wider social inequalities**. For example, women may participate in various activities or tasks as beneficiaries, but when added to housework and community roles, these tasks can overload, and limit their inclusion in the workplace. In so doing it can reinforce traditional roles and sexual division of labour and contribute to gender inequality (Arenas-Monreal et al., 2015).

Secondly, they do not clarify the **preconditions** for any form of participation to be effective. For example co-determination in planning depends on the level of effective decentralisation in the system; while participation in service delivery may be more affected by local staff motivation and their support for community roles (Oxford Policy Management 2013). Potts (2008) observes that exercising the right to participation is affected by personal, interpersonal and institutional dynamics, calling for fair and transparent processes.

This section points to the relevance of understanding the different level, drivers, interests in and sites of participation, within the context of these wider factors and pre-conditions, to better understand how and how far they are building and sustaining meaningful levels of social power and participation within health systems. This is further discussed in *Section 4.*

3.5: Assessing impacts or outcomes of social participation in health

The literature on participation in health systems is often focused on methods and mechanisms, with limited systematic consideration of the extent to which efforts to engage people yield changes in health or in health services (Coney 2004). Although the field is poorly measured, there is some evidence that the social dimensions outlined earlier can enhance knowledge of, uptake, effectiveness, comprehensiveness and equity in health services, action on SDH and positive social perceptions of health (Gilson et al 2008; Coulter 2009, Gaventa and Barrett 2010; Harun et al., 2013; Rifkin 2000; 2001).

As noted earlier, people are more likely to trust, use and respond positively to health services and to take action in or contribute to health if they have been informed and involved in decisions about how these services are defined, organised and delivered. Participatory mechanisms may make decisions and policies responsive to people's needs and more socially accountable in their performance. The effects may be indirect, and on deeper determinants of health such as social inclusion. The literature reports positive effects on self- efficacy, peer norms towards health promoting behaviours, positive self-identity and reduced alienation (Ramirez-Valles 2002). Communities report greater satisfaction with decisions in which they participate, even when participation does not change the outcome or when outcomes are not consistent with their expressed preferences (Oxford Policy Management 2013). Abelson and Gauvin (2006) have also distinguished different areas of outcome to be measured, pointing to process impacts and outcome impacts of participation in health systems, shown below:

Impacts on process	Impacts on outcomes
• Representativeness, inclusivity, participation rate • Early, continuous involvement in planning • Process fairness, flexibility, transparency • Structured decision making • Resource accessibility, Task definition • Independence, Interaction • Comfort, convenience, Satisfaction • Competence • Integration of values, ethics	• Influence on policies/ decisions • Agency responsiveness to participant inputs/demands • Public views incorporated into decisions • Impact on knowledge, awareness, capacities of communities and health workers • Public trust in services; public perception of consultation level • Impacts on cost, performance

There is, however, little evidence that participation measures can substitute for deficits in service provision. The literature also records (such as in involvement in HIV programmes) stress and burnout, with physical and emotional fatigue. Whilst one review of evidence participatory approaches found modestly positive health and social outcomes, the main beneficiaries were observed to be the most literate, the least geographically isolated, and the most politically well-connected. In contrast the burdens may be highest on the least economically secure groups. There is little evidence that *induced* participation builds long-lasting cohesion, even at the community level, and may reinforce existing divisions (Mansuri and Rao 2012). Participation driven by project-related incentives may not last beyond the tenure of the project and the limited evidence indicates that it usually does not. The evidence is thus mixed, and points to obtaining a much deeper understanding of the contexts, conditions for, drivers and interests in, and interrogation of the forms of power and participation than may often be the case in experimental designs (Marston et al., 2013).

It is not possible to be prescriptive on models for assessing these impacts. Dickinson and Prabhakar (2009) use, for example, a logic model / chain to assess impacts of interventions that includes:
- the contextual conditions;
- the strategic priorities and interventions; their assumptions, theory of change, inputs, activities and processes;
- the direct outputs, adjusted for those that have been secured anyway; that may be offset by negative changes elsewhere; or where there is spill-over to other effects or groups; and
- how these outputs are linked to directly and indirectly associated changes and impacts on the conditions that gave rise to the activities, as outcomes.

It is even more difficult to be prescriptive on models for assessing the cost-benefit of participation. There is a serious lack of data on the practical costs and benefits of participation, for a range of practical and ethical reasons. Analyses of the costs and risks of participation have included:
- Monetary costs, including staff time (paid and unpaid), staff expenses, external staff / consultants, fees to participants, participants' expenses, training for staff and participants, administration, venue hire, other event costs (e.g. refreshments, equipment), newsletters, leaflets, monitoring and evaluation fees; and
- Non-monetary costs, including time contributed by participants, and skills needed for the new approach (taking time from other work), and risks, including risks to reputation (from bad participatory practice), stress, uncertainty and conflict.

At the same time, there is a reluctance to quantify benefits of participation, particularly to assign a monetary value to these benefits. Oscar Wilde's definition of a cynic as 'someone who knows the price of everything and the value of nothing' can be taken as a caution here. It is the value rather than the cost of participation that is important, but how do we begin to ascribe 'value' to participation in a coherent and rigorous manner?

There is thus caution on 'measuring' or attributing impact and cost benefit to participatory measures (Involve 2005). More reflexive methods, realistic evaluations and participatory review can, however, be used by those involved to clarify and implement strategic review of the immediate, intermediary and long term process, social and system changes they expect from their initiatives. These can be helpful to assess outcomes and to build confidence in or review the processes. Understanding 'what works' calls also for a clearer understanding of the various enabling and disabling factors that affect the quality of processes for participation and their outcomes. A number of these were observed in the literature:

- As **enablers**: The level of government policy support and the resources and organisation in the system to invest in change are observed to provide supportive contexts, together with the responsiveness of health workers and bureaucrats and the democratic functioning/ representativeness, strength, capacities, resources and space for community roles/input. Process factors identified include the time for, nature, duration and consistency of the processes, the trust in, inclusiveness and accessibility of the processes, the commitment, mandates and skills of those involved and the delivery of visible benefits to the different groups. The ability of communities to exit

official process and apply independent pressure were also identified as enabling positive outcomes, facilitated by pre-existing community organization (Katz et al 2015; George et al., 2015; Rifkin 2000).

- As **barriers:** Conversely a range of contextual factors were observed to block participation, especially for marginalised groups, including cultural, physical, geographical, age, literacy and linguistic barriers, the stigma associated with some conditions; the domination of more elite social groups; lack of trust and support from external stakeholders, negative attitudes of health workers and lack of community confidence in their abilities. Processes barriers raised include the disempowerment from use of technical evidence; from unclear reporting lines and unrealistic operational plans. There may be resistance to power shifts; role strain and time demands; and under-recognition of the roles in incentive systems. Meeting processes, language and pervasive emphasis on consensus may have the effect of discouraging dissent and favouring the views of more powerful actors. Representatives taking on the role of 'gatekeepers,' sandwiched between representing their community and representing the process may also dampen voice and dissent. (Katz et al., 2015; George et al., 2015; Coney 2004; Newbury and Wallace 2014).

These enablers and barriers clearly apply across all the areas raised earlier, in the contexts, the actors and roles, in the health and related systems and in the nature of and processes for participation.

The literature highlights that while it is possible to document contextual, institutional, process, community and other enablers and barriers for participation and the outputs and outcomes achieved, it is significantly more difficult to make causal links and assign cost benefit to these processes, particularly within the limits of a case study design. There are also intangible benefits linked to participation (such as trust, social capital and community cohesion) and costs (eg: in time burdens and social risks). These costs and benefits call for approaches that integrate participants' perspectives and interests. Further, the time frames matter. Effective engagement does not develop within a predictable trajectory. Instead, it often proceeds along a "punctuated equilibrium," with long periods of seeming quietude followed by intense change (Mansuri and Rao 2012).

4.   Generic framework for the project

This section summarises, drawing on the evidence from the literature in *Section 3*, the key features identified for the overall framework for this project, to support a shared understanding of what is meant by social power and participation in health systems, and to support the gathering of evidence on the mechanisms, methods and tools for community participation and decision making at the level of *primary care health services and local governance (local councils*) and in measures for *intersectoral co-ordination* on health.

The framework aims to support the purpose of this project, viz to gather evidence on promising practices in and models of community participation, power and decision-making in health systems from selected high, middle and low income countries; to identify and share learning for adaptation in local or state-wide sites in the USA. Across all its areas of work, the project seeks to gather and share evidence and learning from current practice on:

a. How is social participation being organised in local health systems and in the inter-sectoral co-ordination between health and other sectors? With whom, with what mechanisms, methods, tools and resources; in what area(s) of local health systems functioning and based on what interests?

b. What features of these practices are building, supporting and sustaining authentic (bottom up, self-claimed) social power in local health systems, particularly in co-determining and co-producing health actions and services?

c. What social, health and health system outcomes/changes have been associated these practices?

d. What contexts, conditions, capacities and meso-level measures and mechanisms are enabling and/or disabling promising practices on power and participation?

The evidence in *Section 3* highlights three areas to elaborate to address the first two questions above, viz

1. The nature of the **community actors**.
2. The dimensions of the **health system** within which participation is being exercised.
3. The nature/ features/ organisation of the **participation and power**.

The literature points to two further areas of evidence to address the second two questions, viz::

4. The **context** and enabling/ disabling conditions for participation and
5. **Cross cutting issues** of (a) the strategies and measures used to support participation at the local level, including through meso level institutions; and (b) the social, health and health systems outcomes associated with the work.

Drawing on the evidence in *Section 3,* within these five areas, there are ten more detailed conceptual aspects shown in *Box 3* below.

Box 3: Key elements for the framework to organise evidence on promising practice in social power and participation in health systems

The context for participation:
1. Relevant normative, socio-political, economic, governance and health system context features that affect participation and power..

The nature of community / actors:
2. How the community role is understood in health (as citizen, beneficiary or consumer[3]), and the level of engagement from individual to family, to social group, community and wider public and social levels.
3. The features of the social group involved, their inclusiveness, interests in and capacities for social participation and the mandate/ legitimacy/ voice and capacity of community representatives.
4. The contribution of a range of other visible and invisible[4] actors.

The dimensions of the health system:
5. The dimensions of health system functioning and decision making involved (information; needs assessment; planning and budgeting; policy deliberation; health actions and oversight)[5], and interactions with / integration of other sectors.

The nature of participation and power:
6. The different levels and forms of participation, the extent to which each are externally induced or organic; invited or claimed, and the interests and motivations of system and community actors.
7. The goals of participation; whether around social features, specific issues or diseases; and whether it to work within and improve or to transform current health models.
8. The nature and organisation of the opportunities, spaces, mechanisms, processes, methods, and tools for participation, whether formal and/or informal, sustained/ durable or temporary/transient, who accesses them and how they are used.
9. The forms and levels of power (*over, to, with, within*) being claimed and exercised by community and system actors; in what spheres of decision making, action and control, and with what shifts.

Cross cutting issues:
10. The strategies, processes, resources, tools and capabilities supporting local participation; the enablers and barriers across all areas; and the outcomes in health, health systems, in the actors and changes in power and participation itself[6].

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[3] In some settings related terms may be used for consumer, eg client, beneficiary
[4] As described in Section 3.2 not all who influence processes are directly visibly involved or in public domain
[5] Noting that the focus may be on one or more elements of these, within this project at local level
[6] The project design does not enable original assessment of impact, given complex issues in attribution, but already documented evidence of outcomes associated with participatory practice can be shared.

Box 4 below provides questions that give further detail each of these major areas, to be drawn on as relevant to guide and organise the evidence from literature; from the US sites, from country case studies internationally and in the meta-analysis, moderated discussions and meetings that reflect on the findings[7].

Box 4: Detail on the elements of the framework

The context for participation:

a. What is the population health profile and which groups carry high health burdens?
b. What material, economic, socio-political, institutional beliefs, norms and values, constitutional, legal and policy frameworks support or disable social participation?
c. Is the right to health and to participation incorporated in law, policy and guidance? Is participation embedded in the political culture?
d. How is the health system organised at local and higher levels? Is the public health system universal? Where are decisions made on the financing, services and actions of the local health system?
e. How is the health system oriented / organised to promote population health and to integrate biomedical, psychosocial and ecological dimensions of health? How does it collaborate with/ integrate other sectors that impact on health?

The nature of community/actors

a. How is the role of the public understood in health? Are people viewed in policy or in social discourse as *consumers* (or beneficiaries) or as *citizens*[8]?
b. Who is involved in processes for participation? At what level(s) - as *individuals* (patients, consumers/ users of services; citizens; carers; volunteers); as *family*, as *social group* (civil society, civic network; consumer organisation); as *local community* through to *wider public* and social levels? [9]
c. How do the social groups involved compare with those in the wider community? And with those with highest health burdens? How far do people identify with the social group? What features that enable/ impede or discriminate against involvement for different social groups?
d. What were the motivations for participation, with what interests, and what burdens and risks perceived by community and systems actors? What are the perceived desired levels and forms of participation?
e. What mandate/ legitimacy, voice and capacity do social group representatives have?
f. What other visible and 'invisible' actors contribute to social participation processes and in what role?[10]

The dimensions of the health system:

a. Which dimensions and specific areas of health system functioning and decision making involve participation? In what specific areas? How and with what mechanisms/ processes?
- *Community health literacy and public information*, including use of internet and community knowledge.
- *Assessment, identification and prioritization of health needs and priorities,* including in population registration and enrolment, social mapping and community based research;
- *Health planning and decision making,* including on priorities, resources, budgets, incentives and sanctions, including in relation to health workers/ human resources for health;
- *Health policy deliberation and formulating strategic policy direction*, including on benefit packages, financing, and in the integration of community preferences, values and culture;
- *Co-design, co-ordination and co-production/ implementation of health actions*, including in the integration of client/ community choices and information exchange on services, development and use biopsychosocial and holistic models; in the involvement of community health workers; *in setting and*

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[7] The questions are a comprehensive set and not all are relevant to *all* the work areas in the project
[8] As discussed in Section 3.2, consumers are seen as users of services, (or beneficiaries of insurance benefits) entitled to use, organise, make rational decisions on, co-determine services and hold them to account. They may be seen as citizens, with rights to organise, engage, co-determine, act and hold the state to account on health rights and responsibilities, for themselves and for society as a whole. They may be seen as both in different aspects of the system.
[9] Questions (b)-(e) may have different responses for different dimension(s) of health systems outlined below
[10] including social organisations, social movements and networks; health activists, brokers and mediators

implementing measures for service quality, in inter-sectoral action on health and social determinants; and in the use of health information and electronic records in services.

- *Oversight, monitoring, evaluation and review of services/actions*, including to monitor and assess responsiveness, satisfaction, social and health outcomes, service performance, quality and accountability against commitments; to control corruption in use of public funds; and through participatory research and use of the information system and information technologies / social media.

The nature of participation and power in the system, practices described[11]:

a. How does the public express their demands and views in health? Through what channels?
b. How are individuals and families empowered / disempowered in their relationships with health system?
c. Who initiated the participation, with what interests and motivations of system and community actors? To what extent is it top-down/ externally induced[12] or organic/ self-determined? Was it invited or claimed?
d. Around what issues and goals is participation organised- (on social features, specific issues / diseases/ services/ SDH or other areas)?
e. How is participation organised? At what levels (manipulation, informing, through to consultation, to partnership and delegated power through to co-determination and citizen control)? By and with whom? Who accesses the processes?
f. Is participation is through sustained / durable processes[13] and/ or temporary / transient (one off) processes, spaces and mechanisms? Within what formal/ informal; open/closed spaces? With what mechanisms, processes, tools and resources?
g. How do these processes relate to the locus of decision making or control in key system functions? How accessible, fair and transparent is decision making? With what grievance process?
h. What are the interests, incentives and expected benefits of the community and of the system actors in applying participatory approaches? What are the risks, burdens and disincentives?
i. What forms and levels of power , autonomy, and control are being exercised by community and system actors in these processes?[14] What shifts in power have taken place?

As cross cutting issues:

a. What specific strategies, processes, resources, and tools are being applied, by whom, to support communities and health systems in the mechanisms, processes and capabilities for participation?
b. How has information technology/ social media affected participation and power of different actors?
c. How are the interactions between the different dimensions (actors, system functions, forms of participation) producing positive (or negative) feedback loops over time?
d. What meso-level structures, alliances, processes and support are being applied?
e. What enablers and barriers[15] are affecting and sustaining processes across all areas?
f. What are the outcomes in health, health and related systems, in the actors and their social power and participation?[16] Are any attributable directly to the participation intervention?

While the different areas of work (literature, briefs and case studies) will each apply the broad framework in *Box 3*, the included elements from *Box 4* will be those that are relevant to that area of work.

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[11] The responses may differ for different specific dimension(s) of health systems outlined above, and there may
[12] Including through externally led consultations or incentives
[13] Such as statutory bodies, co-management committees, councils, local governance, service user groups
[14] Including controlling 'power over'; the internal capacity and consciousness of 'power within'; the ability to act in 'power to' and the 'power with' created in collective action.
[15] In contexts, such support by authorities, democratic space, in systems, such as consistency of process, delivery of benefits, in actors, such as community autonomy, elite domination, weak collaboration, and ion the nature of participation, such as time demands, language and processes
[16] Including social outcomes such as social inclusion, norms and interaction and substantive outcomes in relation to policies, decisions, capacities, knowledge, satisfaction, trust, performance and cost and in relation to health and health systems.

Appendices 1-3 outlined specific proposed templates for
  i.   the annotated bibliography (*Appendix 1*, already underway);
  ii. the briefs on current practices and challenges in the US sites (*Appendix 2*, to be finalised in dialogue with the sites in April 2016) and for
  iii. the international country case studies (*Appendix 3,* to be drafted and reviewed July – October 2016).

Presenting these broad elements in a list as above masks the importance of showing how they interact, at different forms and levels. This interaction is important to understand, to reflect and draw insights on both the conditions for and forms of participation that may have benefit for health. In any 'story' of social power and participation in health, there may be multiple levels and forms of these elements at the same time, with changes and feedback loops within and across them over time. To better understand these relations, Levasseur et al., (2013) thus calls for frameworks that integrate the multidimensionality of the who, how, what, where, with whom, when and why of participation.

Various efforts have been made conceptually to achieve this, and to bring together the different levels and dimensions of social power and participation in health systems that were described in *Section 3*. Davies in 2009 set a matrix of participation, for example, that combines the 'ladder' of levels on its vertical axis with a spectrum of measures for participation on its horizontal axis, ranging from informal to formal measures, to reflect both the diversity and possible progression of options (Karsten 2012).

Charles and DeMaio (1993) present a further, example, with three elements in a 3 x 3 model, viz:
- The role of community (as policy actors or users)
- The domain of decision making, and
- The level of participation.

This model, shown in *Figure 3*, shows graphically the different gradations of these three elements in relationship to the others.

Gaventa (2006) also presents a 3x3 cube, with the levels (local to global); spaces (closed to claimed) and forms of participation (visible to hidden) to facilitate thinking about openings, levels and strategies to exercise agency.

These approaches attempt to integrate the interactions of the different dimensions and drivers of participation raised earlier. They have limitations, in that while they show interactions of the different elements, this is still presented as a rather static picture. It is rather more dynamic, with different elements interacting at different levels over time, with varying effectiveness and feedback loops on each other.

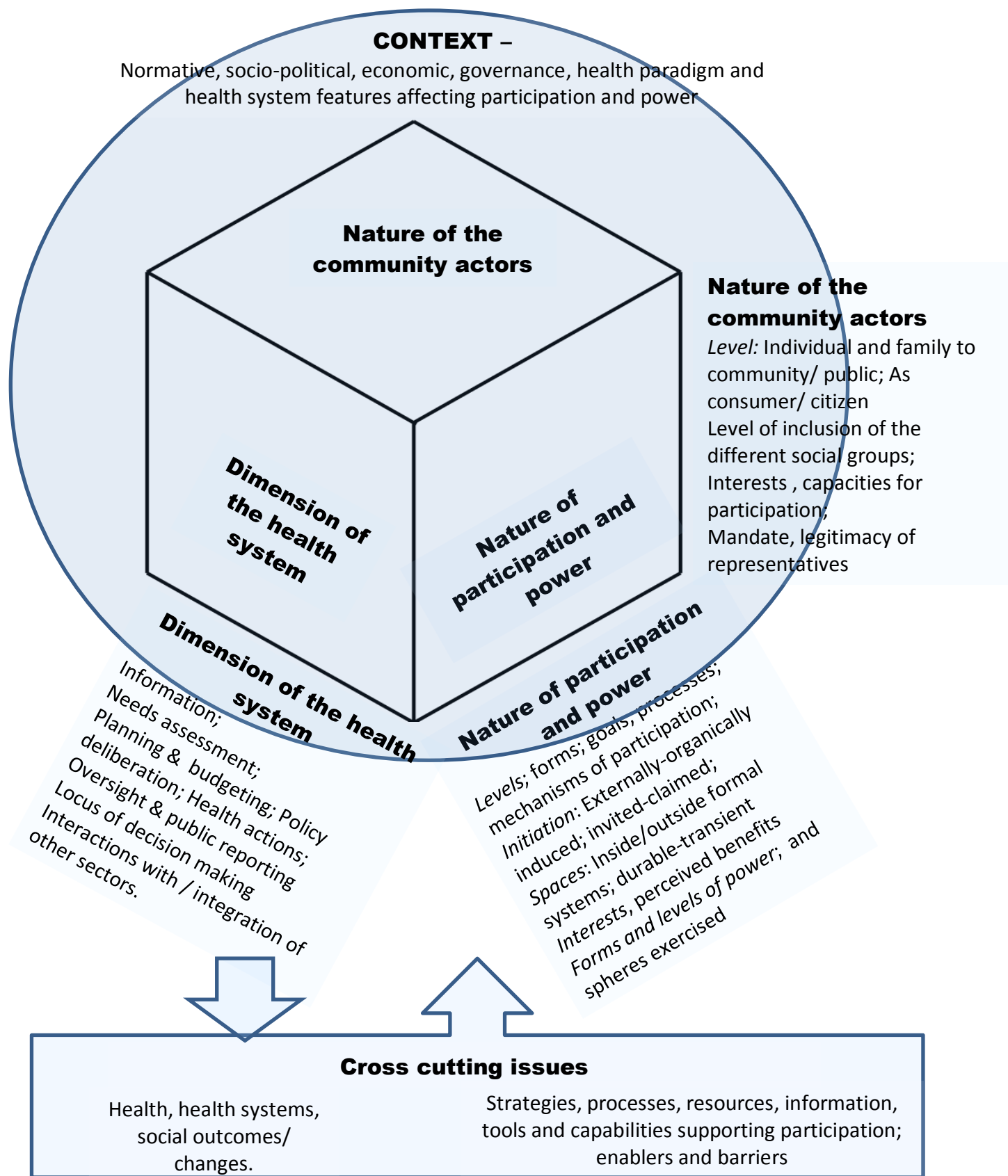Figure 3: Dimensions of participation in health care
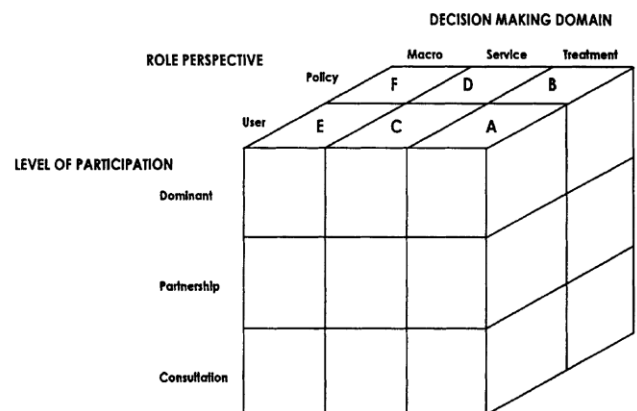
Source: Charles and DeMaio 1993 p891.

Notwithstanding this limitation, we suggest in *Figure 4* a visualisation of the interactions between the different elements for this project. At the *centre is the case study / analysis of promising local practice.* It is shown as an interaction between the nature of the community and other actors; the dimensions of the health system involved and its interaction with other sectors; and the nature of participation and the social power generated. It integrates in each the issues outlined in *Box 3*, to describe "the who, how, what, where, with whom of participation" at local level of health systems, and their interaction to generate different forms of power in decision making and action on health. The framework aims to guide a rich description of the local level, an understanding of the positive and negative feedback loops between the different elements and how they link to the intended and realised social, system, process and health *changes and outcomes*.

To contextualise and deepen the understanding of this local level experience, the framework in *Figure 4* locates this local level within the *wider contextual conditions* affecting it. It also draws attention to the *meso-level measures and mechanisms* that enable, support and sustain the local level experience, to understand how they affect each of the three central elements, and the interactions between them.

Figure 4: Multidimensional framework for organising evidence on experiences of how social power is being organised at the community and primary level of the health system

CONTEXT –
Normative, socio-political, economic, governance, health paradigm and health system features affecting participation and power

Nature of the community actors

Nature of the community actors
Level: Individual and family to community/ public; As consumer/ citizen
Level of inclusion of the different social groups;
Interests , capacities for participation;
Mandate, legitimacy of representatives

Dimension of the health system

Nature of participation and power

Dimension of the health system
Information;
Needs assessment;
Planning & budgeting; Policy deliberation; Health actions;
Oversight & public reporting
Locus of decision making
Interactions with / integration of other sectors.

Nature of participation and power
Levels; forms; goals; processes;
mechanisms of participation;
Initiation: Externally-organically induced; invited-claimed;
Spaces: Inside/outside formal systems; durable-transient
Interests, perceived benefits
Forms and levels of power; and spheres exercised

Cross cutting issues

Health, health systems, social outcomes/ changes.

Strategies, processes, resources, information, tools and capabilities supporting participation; enablers and barriers

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Appendix 1: Template used in the annotated bibliography

Area	Issues for inclusion
Country(ies)	What country/countries is the participation/ empowerment process in? At what level of the health system (local/ primary care, meso/state/regional; national; cross national) With what other sectors involved?
Context	Relevant social, political, cultural, environmental, economic, governance context factors Population health orientation; service outreach in the health systems? Social groups / differentials in the catchment community?What motivated the participation/ empowerment processes? In response to what problem(s)? What community is covered by the process(s) Who introduced the participation/ empowerment processes? How was it set up- by whom, with what external input/ support?
Objectives	What are the objectives of the participation/ empowerment processes for the community and for the health system? Who set the objectives? Who is responsible for monitoring and ensuring delivery on the objectives? What is the role of the community? What plan for sustainability at the onset?
Dimensions	What are the dimensions of engagement, in which functions? How are they implemented? By whom? With what financial and non financial inputs for the set up, running costs? From whom?
Cross cutting issues	a. What specific strategies, processes, resources, tools and capabilities are being applied to support the participation mechanisms, processes, outcomes, from both communities and health systems? b. How do these different elements interact, with what changes and feedback loops over time? c. With what support for /investment in competencies in the community, health and other systems? d. What meso-level structures, alliances, processes and support are being applied? e. What are enablers and barriers[17] are affecting and sustaining processes? f. What are the social, health, health system and other outcomes?[18] Are any attributable directly to the participation intervention?
Roles	Aimed at what range of individual -> population/ community involvement?
Change/ outcomes/ impacts	With what outputs? What changes and outcomes? What (measurable/ other) results on participation, power, systems, health, costs? With what confounders? What unintended outcomes? What spillover effects? What longer term / sustained changes?
Enablers/ barriers	With what barriers/ enablers?
Scale up/ spread	With what activities planned or implemented for scale up/ expansion implemented? Through/with whom? Supported by whom? With what resources? What enablers/ barriers to scale up?

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[17] such as in relation to support by authorities, democratic space, consistency of process, delivery of benefits, community autonomy, elite domination, weak collaboration, time demands, language, processes -

[18] Including social outcomes such as social inclusion, fairness, transparency, social norms and interaction and substantive outcomes in relation to policies, decisions, capacities, knowledge, satisfaction, trust, performance and cost and in relation to health and health systems.

Appendix 2: Template used for US site evidence

Purpose: The US site brief aims to identify the gaps and opportunities for building community participation, power and decision-making for improved population health in health systems and SDH, noting the health system and community features of the site and the inclusiveness of the approaches, as input to ascertain the areas of focus for the international work

Area	Issues for inclusion
Site	Name, health system level[19] and location and map of the site catchment area Focal point and position
Context for social participation	**What are the health issues and systems that affect social participation in health?** a. What is the population of the site? With what different social groups? b. What is the major population health profile in the site? What are the main health burdens? Which groups have high health burdens? c. What socio-economic factors and legal and policy frameworks support or disable social participation? d. How is the health system[20] organised at local level? Who is involved? e. Where are decisions made on services and financing? f. How is the health system oriented / organised to promote population health? Does it integrate psychosocial and ecological dimensions of health? g. How does it collaborate with/ integrate other sectors that impact on health? h. What context factors are enabling and what barriers are disabling social participation in the local community?
The nature of the community/ actors involved	**What features of the population and system actors affect participation?** a. Who is involved in processes for participation in health in the site? At what level(s) - as individuals (as patients / service consumers or as residents?); as family, in specific social groups (which?); as the catchment community and /or wider public? b. How do the groups involved compare with those in the wider local community? And with those with highest health burdens? What features enable/ impede or discriminate against involvement for particular social groups? c. What were the motivations for participation, with what interests, and what burdens and risks perceived by community and systems actors? What are the perceived desired levels and forms of participation? d. What social groups have representatives involved in the local health system? How were they chosen? What mandate/ legitimacy, voice and capacity do these social group representatives have? With what gaps/ deficits? e. What other actors contribute to social participation processes and in what role? f. What social factors (and for whom?) are enabling and what barriers are disabling people participating in the system from the local community?
The dimensions of the health system within which participation takes place	**Where is social participation currently being applied in the health system?** a. Which functions and areas / programmes in the local health system functioning[21] currently involve community participation? b. Which involve communities directly in decision making? c. What areas of intersectoral co-operation for health in the site involve community participation? d. In each case, how is this being implemented? Involving whom? With what mechanisms/ processes? e. In what areas of local health system functioning are the community or system

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[19] Eg whether primary care centre; area health service; county health service; etc

[20] A health system (health care system) refers to the organization of people, institutions, and resources that deliver health services and undertake activities whose primary purpose is to promote, restore, and maintain health.

[21] Including within the areas shown in the framework p21.

Area	Issues for inclusion
	actors seeking to *strengthen* community participation? Why? f. What challenges are being faced? What factors are enabling participation in these areas of local health systems, and what barriers exist?
The nature of the participation in the local health system	**What are the features of and challenges in social participation initiatives?** For the key area(s) of participation you are implementing / seek to implement in the local health system, noting also any important changes over time: a. Who initiated the participation? To what extent was it top-down/ externally induced or organic/driven from within the community? b. What were the interests in and motivations for participation the system and community actors? c. Around what issues and goals is participation organised? d. What processes are being used? How sustained are the processes? Are they formal or informal? How accessible are they to the community? e. What tools and resources are being used/provided? f. What is the current level of participation: Would you describe it as: Manipulation / informing/ consultation/ partnership / delegated power / co-determination or community control? What power do community actors have in decision making? Who is bound by decisions that communities participate in? g. What incentives and expected benefits do the community and system actors perceive in being involved? What are the risks, burdens and disincentives? h. In what processes, including for decision making, do the community or system actors seek to strengthen participation? What challenges are being faced in doing this? What factors in the community or the system are acting as barriers or disabling effective participation?
Cross cutting issues	**What support do these initiatives obtain, with what gaps and challenges?** a. What measures are being used to support or scale up community participation? Who is providing this support? What gaps or challenges are being faced in providing capacity and other support to participatory processes? b. How has information technology/ social media been used to support participation of different actors? c. What social, health and health system outcomes or changes have you found to date arising from your participation interventions? In whom?
Issues for international learning	**What evidence would the site seek to obtain from international experience?** a. Overall, what challenges, gaps and opportunities for building community participation are seen as priority areas for the site? b. What evidence would the site seek to obtain from international case studies? c. Has information from other countries internationally already been applied in the site? From which countries?

Appendix 3: Template for the international case studies

The case studies aim to share evidence[22] and experience on

- meaningful ways of organising community participation, power and decision-making in local health systems and in arrangements and measures for inter-sectoral co-ordination between health and other sectors relevant to improving health and the social determinants of health;
- the mechanisms, methods and tools used; contexts, meso-level support, enabling factors and challenges faced, especially for inclusion and power of the most at risk and marginalised groups; and how they are being addressed; and
- the health, social and institutional outcomes of the approaches used.

Specific terms of reference will be developed for *each* case study, differentiating on the level of detail and scope between the six deeper scan case and the six short case studies[23], 'to tell the story' of the specific country and site practices. These generic templates will be reviewed in the September 2016 meeting.

Col 1: Area	Col 2: Issues for inclusion
Background	
Site	Name of the country and of the site(s) located on a map, health system level[24] and practices covered in the case study. Focal point(s) for the site(s) and their position and contacts for follow up interaction Case study lead and team members[25] Key informant sources
Context for social participation	**What contextual features affect social participation in health, generally and in relation to the specific site(s)/ practices covered?** A brief general description of the country, population, socio-economic and population health profile and organization of the health system, followed by more specific information for the site(s)/ areas included in the case study - with analysis of their influence as relevant on participation – for: a. The social groups, main health burdens and their social distribution b. The beliefs, norms and values and constitutional, legal, policy and rights frameworks and cultures that positively/ negatively affect participation in health. How the public role in health is understood. c. The local organization of the health and related systems (eg local government) and where decisions are made (eg on financing, services) d. The orientation of the health system and its integration/ collaboration with other sectors to promote population health and to integrate biomedical, psychosocial and ecological dimensions of health. e. How the public expresses their demands and views in health (through what channels?). How individuals and families are empowered / disempowered in their relationships with health system.
For the specific promising practices/ sites in the case study	
Outline the practices in focus, and how they seek to change/ improve health/ the health system	**What areas of/ practices in social participation in health are covered in the case study, with what goals or intended changes/ improvements in health/ the health system and what understanding / intention of how they will achieve these changes?** A brief outline of the key area(s)/ practices involving participation covered in the case study, noting also any important changes over time, with:

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[22] The case studies will present text, graphic and visual evidence and link to videos where feasible, Deeper scan case studies will provide evidence from published and grey literature and primary evidence from sites and key informants; Short case studies will collect evidence from available document/ websites and key informant interview.

[23] The shorter case studies will have significantly more focused terms of reference.

[24] Eg whether primary care centre; local government area health service; primary care service, ; etc

[25] The lead, relevant team and site members would be included as participants in the web platform

Col 1: Area	Col 2: Issues for inclusion
	a. Their origin/history and what motivated or who initiated them (how top-down/ externally induced to organic/driven from within the community), and how support was built. b. The population health/ health system issues they aim to address, their goals and how they seek to change/ improve health and the performance of the health system[26]. c. The interests in and motivations for the practices and changes.
Describe the nature of the community/ actors involved	**Who is involved and what features of the population and system actors affect participation?** Presentation of the social actors involved- with analysis of features that enable/ impede participation or affect the forms of participation – for: a. Who is directly involved in the processes (and how this group compares with the wider local community and the distribution of health risk/burdens), at what levels (as individuals, family, community, as patients or residents), whether directly or through representatives, and connecting how with community resources and networks. b. If through representatives how were they chosen (and by whom)? What mandate/ legitimacy, voice and capacity do they have? c. The motivations for participation and what benefits, burdens and risks perceived by the community and health system systems actors. d. What other actors contribute to the participatory practices and in what role[27]?
Describe and analyse the nature of the participatory practices in the different dimensions of the health system in the case study site(s), how they are actually functioning and how are they perceived by those involved to have affected the desired changes/ outcomes	**Where and how is social participation currently being implemented in the health system?** Describing the areas of functioning of the health system[28] that involve the participatory practices covered - with analysis of the system factors that enable/ disable participation or affect the forms it takes– and making clear for the different practices: a. In each case, how this is being implemented, involving whom, with what mechanisms, processes, tools and resources. b. How information technology and social media is being used. c. Which involve communities directly in decision making and how d. Which involve, or are enabling intersectoral co-operation, collaboration or integration for health and what role community participation plays in this. e. How the practices are being developed, changed, sustained over time, in response to what factors, and with what changes in system or social roles. d. What inputs are being provided from higher levels of health or other systems, alliances, networks to support or scale up the practices, by whom and through what strategies, resources or tools. f. What areas of the local health system functioning community or system actors are seeking to further *strengthen* community participation, how and why. *Continued overleaf…*

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[26] Noting US site interests in overcoming social exclusion and reaching marginalised groups; in chronic conditions (mental health, opiod addiction, heart disease, obesity, food insecurity) and SDH (food, physical activity etc)
[27] Eg social organisations, social movements and networks; health activists, brokers and mediators
[28] Including within:
a. Community health literacy and information, building political, stakeholder, public awareness/engagement, raising attention of organisations needed for change and to resource work
b. Assessment, identification and prioritization of health /SDH needs and priorities, that trigger social, policy recognition;
c. Health planning and decision making, including on priorities, resources, budgets, incentives and sanctions, including in relation to health workers/ human resources for health;
d. Health policy deliberation and formulating strategic policy direction, including on benefit packages, financing, and in integration of community preferences, values and culture;
e. Co-design and co-implementation of health culturally appropriate actions, including community health workers; changing health culture; and supporting service uptake for key groups and
f. Oversight, monitoring, evaluation and review of services/actions, including responsiveness, satisfaction, social/health outcomes, and service quality and accountability.

Col 1: **Area**	Col 2: **Issues for inclusion**
Describe and analyse the nature of the partici-patory practices in the different dimensions of the health system in the case study site(s), how they are actually functioning and how are they perceived by those involved to have affected the desired changes/ outcomes	**What are the features of and challenges in these social participation initiatives/practices and how are they perceived by those involved to have affected the desired outcomes/ changes?** Individually for key area(s) of participation covered in the case study, analyse, noting any important changes over time and the factors, challenges and enabling conditions that have affected practices and the changes intended: a. How sustained / durable are the processes, spaces and mechanisms[29] or temporary / transient (one off)? What has affected this, and if sustained, what has sustained them? b. Are they formal or informal? How accessible are they to the community? What has affected their accessibility? c. What is the current level of participation: Manipulation / informing/ consultation/ partnership / delegated power / co-determination or community control? d. What forms and levels of power and control are being exercised by community and system actors in these processes? What power do community actors have in decision-making? Who is bound by decisions that communities participate in? e. What capacities /capacity inputs (staffing, skills, resources, purchaser relationships; governance) have facilitated, supported and sustained community roles and power? f. What challenges, barriers, from what source and managed how? g. How have these features affected the practices and the changes they intend to lever?
Document social, system/ process and health outcomes	**What process, social and health outcomes/impacts associated with these participation initiatives have been documented from prior evaluations or are perceived by key informants?** Outline using evidence from existing evaluations or as reported by KIs (citing sources or type of KI) any social, health, health system outcomes or changes found to date associated with the participatory practices and any that may be more directly attributed to them.
Key insights and areas of learning	
Highlight key learning/ Insights for inter-national exchange	**What practices, measures, tools from the case study may be adapted/ adopted in other settings and what insights/ learning shared?** a. What insights and learning on social power and participation in health the case study provides for the case study country and for international exchange. b. What features of the practices could be adapted/ adopted in other settings. c. Whether experience from the country/ site has already been applied elsewhere.

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[29] Such as statutory bodies, co-management committees, councils, local governance, service user groups