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Using the Power Wheel as a reflective tool to promote equity, diversity and inclusion in spaces and places of patient engagement.

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Abstract

An important but challenging aspect of patient engagement is including diverse perspectives. Inclusive patient engagement facilitates the involvement of individuals from structurally marginalised communities so that decision-making reflects the needs and priorities of all people. When underrepresented, under-resourced, and underserved individuals are equitably involved in decision-making we can prevent a widening of health inequities that may occur when patient engagement activities are only accessible to those living with privilege. Typically, a lack of material resources, exclusionary institutional processes, and engagement practices that are not inclusive in design lead to the engagement of patient partners with access to material, cultural and social resources. This results in services, policies and research designed without contributions from diverse perspectives, creating a healthcare and research ecosystem that reinforces structural marginalization and perpetuates health inequities. In this paper, we build on Gaventa's conceptualisation of the power cube; our own experiences co-designing Equity Mobilizing Partnerships in Community (EMPaCT), an award-winning, spreadable and scalable innovation in equity-focused patient engagement; and over 30 years of collective experience as patient partners involved in healthcare research, policy and practice. Specifically, we describe an interactive Power Wheel that can be used to analyse the interspersion of power in the places and spaces of patient engagement. We leave readers with tools to help illuminate opportunities for equitable transformation and social inclusion so that health services can meet the needs and priorities of all people.

Strengths and limitations

- Power asymmetry is pervasive in the spaces and places of patient engagement – this is most pressing for individuals who have experienced harm by the healthcare system.
- Few actionable tools exist to support praxis (reflection + action) so that power can be better shared with individuals who have diverse intersectional lived/living experiences.
- We have co-designed a Power Wheel to illuminate opportunities for transformation and social inclusion within the spaces and places of patient engagement so that they are oriented towards a goal of improving health equity.
- Conceptual tools may do little to challenge the social and structural inequities that underpin experiences of trauma, oppression and discrimination within patient engagement settings.

Declarations

Ethics approval

No ethics approval was needed for this commentary as no data was collected or analysed to inform the manuscript.

Authors' contributions

Ambreen Sayani, Emily Cordeaux, Omar Khan and Alies Maybee contributed to the manuscript conception and design. The first draft of the manuscript was written by Ambreen Sayani. Emily Cordeaux, Kelly Wu, Fatah Awil, Victoria Garcia, Ryan Hinds, Tara Jeji, Omar Khan, Bee Lee, Alies Maybee, Desiree Mensah, Linda Monteith, Mursal Musawi, Marlene Rathbone, Jill Robinson, Ambreen Sayani, Staceyan Sterling, Dean Wardak, Victoria Forster commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Competing interests

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Patient partner, Marlene Rathbone passed away in July 2023. Her legacy and wisdom is deeply entrenched into the values and mission of EMPaCT. Marlene's message was simple, "Be kind, be compassionate and just listen."

Introduction

Health systems are increasingly recognizing the importance of actively involving patients in decision-making to achieve the Quintuple Aim, focused on improving patient experience, population health, work-life of healthcare providers, reducing costs, and promoting equity [1]. Patient engagement is the active collaboration between patient partners and healthcare partners across various decision-making roles and capacities that encompass clinical practice, policy and research. Patients play a crucial role in redesigning care to meet patient needs, enhancing the relevance and impact of care and optimizing cost-effectiveness [2,3]. In this article, we use the term "patient partner" to reflect all roles where patients and caregivers are involved in health system decision-making. Other common terms include patient/caregiver partners (P/CPs), patient advisors, patient experience advisors, or persons with lived experience (PWLE). [4,5]

A significant challenge in promoting health equity through patient engagement is ensuring diverse perspectives are included in decision-making. In particular, engagement with individuals experiencing marginalizing societal conditions created through historical and systemic discrimination (i.e., low income, low literacy level and/or lack of fluency in the dominant language, gender, sexual orientation, racialization, Indigenous identity and ancestry, disability, and housing insecurity or homelessness) [6] is a crucial step in developing inclusive services and policies that promote equitable access to health care and subsequently health outcomes. Exclusionary patient engagement can occur due to a lack of material resources, prohibitive institutional practices [7] and engagement processes that are not inclusive in design [8]. For instance, diverse and structurally underserved patients tend to be underrepresented through ***institutional patient engagement models*** such as Patient and Family Advisory Councils (PFACs) or patient partner rosters. This is in part because they are less likely to hold a prior relationship with the institution because of historical trauma, stigma or discrimination[6]. Currently, institutional patient engagement tends to primarily involve individuals possessing the necessary resources, connections, and familiarity with the healthcare system. A recent Canadian survey found that most patient partners are female, white, university-educated, and born in Canada[4]. This underscores the lack of diversity among patient partners and shows how social structural privilege shaped by access to material, social and cultural capital reinforces the status quo and can perpetuate structural marginalization [6,9].

Learning from an innovation in diverse and inclusive patient engagement – Equity Mobilizing Partnerships in Community (EMPaCT)

As members of Equity Mobilizing Partnerships in Community (EMPaCT), an award-winning innovation in equity-focused patient engagement, we have direct experience in challenging power dynamics that often prevent diverse patient partners from engaging in health system decision-making. Based out of Women's College in Toronto, Canada, EMPaCT is a co-designed ***community table model*** of patient engagement centered around improving health equity. EMPaCT was co-initiated in response to exclusionary patient engagement practices by applying principles of equity-oriented (engaging with those least likely to be included with the greatest amount of outreach) and trauma-informed (nurturing relationships of trust that recognize structures and systems of oppression) approaches to patient engagement [6,9]. Members of EMPaCT co-designed how, why and when they wanted to be engaged in projects. They co-developed a process to translate their collective lived experiences into a Health Equity Analysis (HEA) for decision-makers. Decision-makers (such as policymakers, researchers and clinicians) request a seat at the EMPaCT community table, flipping power dynamics such that patient partners decide who they will engage with, the time and place of engagement, appropriate compensation for their expertise, and accountability structures for decision-makers who engage with them. Individuals on the table have a safe space within which to share insights and influence recommendations giving them a power not usually available to them within other models of engagement.

In this article we respond to questions we are frequently asked by researchers, clinicians, and decision-makers in health systems given our experiences in patient engagement innovations, specifically EMPaCT[6,9] and over 30 years of collective experience as patient partners involved across the healthcare ecosystem. Some of these questions are:

1. How can we engage with diverse patient partners?
2. Why is it so challenging to maintain engagement with diverse patient partners?
3. How do we move from tokenism to more meaningful engagement?
4. How can we engage more inclusively within the confines of current systems and structures?

To respond to these questions, we begin by exploring how concepts of power relate to patient engagement and issues of Equity, Diversity and Inclusion (EDI). Next, inspired by Gaventa's conceptualisation of the power cube, we introduce readers to the ***Power Wheel***, a tool to unpack and understand issues of power as they relate to patient engagement and EDI. We leave readers with tools to better understand and transform spaces and places of patient engagement so that they can become more diverse, inclusive and equitable aligning with the goals of the Quintuple Aim.

Concepts of power as they relate to patient engagement and equity, diversity and inclusion

Power dynamics within engagement practices and between social relations is an underexplored area in patient engagement. Power can be understood as the ability (agency) of an individual (agent) to act. In the literature on power relations, the ability of an agent to create an outcome is described as, 'power to'; and the concept of 'power over' refers to the asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other. In contrast, 'power with' is the ability of a group to act and mobilize together towards a collective outcome [10–12]. Power is mediated through social relations and legitimized through social practices such as language, policies and the production of knowledge [13,14].

In the context of patient engagement, power relates to the ability (agency) of patient partners (agents) to influence the outcome of decision-makers (actors) in the healthcare ecosystem. In patient engagement, power differentials are commonplace, as patient partners are often not involved in priority setting or direct decision-making. This leads to tokenistic patient engagement practices, where patient partner perspectives are not listened to or reflected in decision-making [15,16]. In the context of diverse patient engagement, power influences who can participate in decision-making; and determines the degree to which decisions are inclusive of diverse perspectives towards a goal of improving health equity. 'Power to' in patient engagement is the ability of patient partners to engage in healthcare decision-making; and when applying an equity lens, means the ability of diverse individuals to be included as patient partners in decisions. ‘Power over’ is the ability or degree to which patient partners can influence decision-making to improve healthcare; and through an EDI lens is the degree to which diverse individuals inform decisions. Finally, ‘power with’ is the ability of patient partners to be equal partners in decision-making; and through an EDI lens is the degree to which diverse patient partners are equal partners in decisions. Reflecting on power in patient engagement is important for increasing patient power influence broadly; and critical when seeking to improve equity, diversity and inclusion in patient engagement.

The Power Wheel

The Power Wheel is a tool that can be used to interrogate power relations in patient engagement, and promote learning, reflection, and transformative action so that places and spaces of patient engagement can become more inclusive of, and accessible to, diverse patient partners with a goal of improving health equity. The Power Wheel is an adaptation of the power cube, a concept first published in 2005 by John Gaventa as he reflected on citizen engagement and governance in the field of international development[17]. Gaventa was concerned with the spaces of engagement, the places, and levels at which citizen engagement was occurring and the interspersion of power within these dimensions [17]. While the power cube has been used to conduct power analyses in a variety of different settings[18] to our understanding, we are the first to adapt it to the field of patient engagement as a Power Wheel.

The Power Wheel (Figure 1) consists of three dimensions (***place, space and influence***) and each dimension has different levels through which power can be understood, configured and reconfigured through ongoing reflection and analysis. ***Places*** are socially constructed areas where social, political and economic power are held. The place of a patient engagement activity directs the levels where agents can exert influence, with each level interrelated to the others. Places of patient engagement occur at the micro level, such as a healthcare system project that is the reason for patient engagement; the meso level, institutions where patient engagement occurs and the funding bodies responsible for resource allocation; and the macro level, the jurisdictions where high-level decisions are taken which impact health and social systems and influence patient engagement activities. ***Spaces*** are the physical or abstract settings shaped by social and cultural forces where interactions take place between agents. Spaces can take three forms: closed, where decision-making occurs without patient engagement; invited, where patient partners are invited into healthcare spaces to contribute their perspectives on a predetermined topic or area of study; and created, informal or formal places where patient partners come together around a common need, and create their own boundaries around priorities, policies, and programs. Finally, ***influence*** is social power where a social relation between two or more individuals influences an outcome such as a decision. Influence can take four forms in patient engagement activities: inform, where patient partners are merely provided with information about what is being done and what it means for them, and do not influence outcomes; consult, where patient partners are involved in providing feedback and input on a specific project; collaborate where their input is taken into account when decisions are made; and decide, where patients prioritise and decide what is relevant and important, and decisions are made by patients and implemented by institutions and projects.

INSERT: Figure 1: The Power Wheel

Using the Power Wheel to analyse power in places and spaces of patient engagement

Researchers, clinicians, and decision-makers in health systems can use the Power Wheel to reflect on and analyse the various dimensions of power within their patient engagement practices and identify ways to transform spaces and places of patient engagement so they become more equitable in alignment with the goals of the Quintuple Aim. Based on our experiences, we are aware that many ***institutional models of patient engagement*** are primarily micro-level places, within which the invited spaces are most accessible to patient partners with higher levels of social, cultural and material capital who are ultimately involved in influencing decisions based on their own level of individual agency. On the contrary, organic, co-designed, ***community-table models of patient engagement*** such as EMPaCT are co-created safe spaces that are places for micro, meso and macro-level transformative decision-making and influence. We recognise that it is not always possible to implement a community-table model of patient engagement such as EMPaCT to support EDI. The EMPaCT model however, does create opportunities for lessons to be learned through reflection and ongoing analysis. Power asymmetries are pervasive in the spaces and places of patient engagement. We urge readers to identify which opportunities exist or can be created to share power within the confines and contexts of their own patient engagement practices. In doing so, individuals who have been harmed and/or systemically excluded will have opportunities to safely influence decisions that affect their own health and well-being.

Taking action to promote equity, diversity and inclusion in patient engagement

There are multiple ways to address EDI in patient engagement. This paper addresses one of the most important ones – the inclusion of diverse patient partners in decision making so that the needs and priorities of more people can be met. This is a key step towards improving health equity through the health system – the opposite of this, designing care with and for only people with privilege can perpetuate the status quo, further marginalise groups that have been excluded, and amplify harms and inequities. We must take every effort to avert this scenario.

We recognize that most often, patient engagement activities have little to no influence on the determinants of oppression and exclusion. Similarly, the Power Wheel is also limited in its ability to conceptualize the political and economic inequities that create social structural exclusion. However, there are ways for patient engagement practitioners and teams to engage in bottom-up action through authentic, meaningful and diverse patient engagement, which can in turn create avenues for collective dialogue and policy-influence. It is only by accruing power back to individuals from structurally seldom-heard communities that we can begin to advance equity. When used as a tool for ongoing reflection and dynamic action, the Power Wheel enables us to rethink and redesign spaces and places of patient engagement to promote equity. Ultimately, the practice of equity-oriented patient engagement is a pursuit of social justice. It is a commitment to redress power inequities in spaces and places of patient engagement so that everyone can be equally involved in crafting priorities, influencing decisions that matter to them, and evaluating the impact of engagement on the betterment of their own personal and collective lives.

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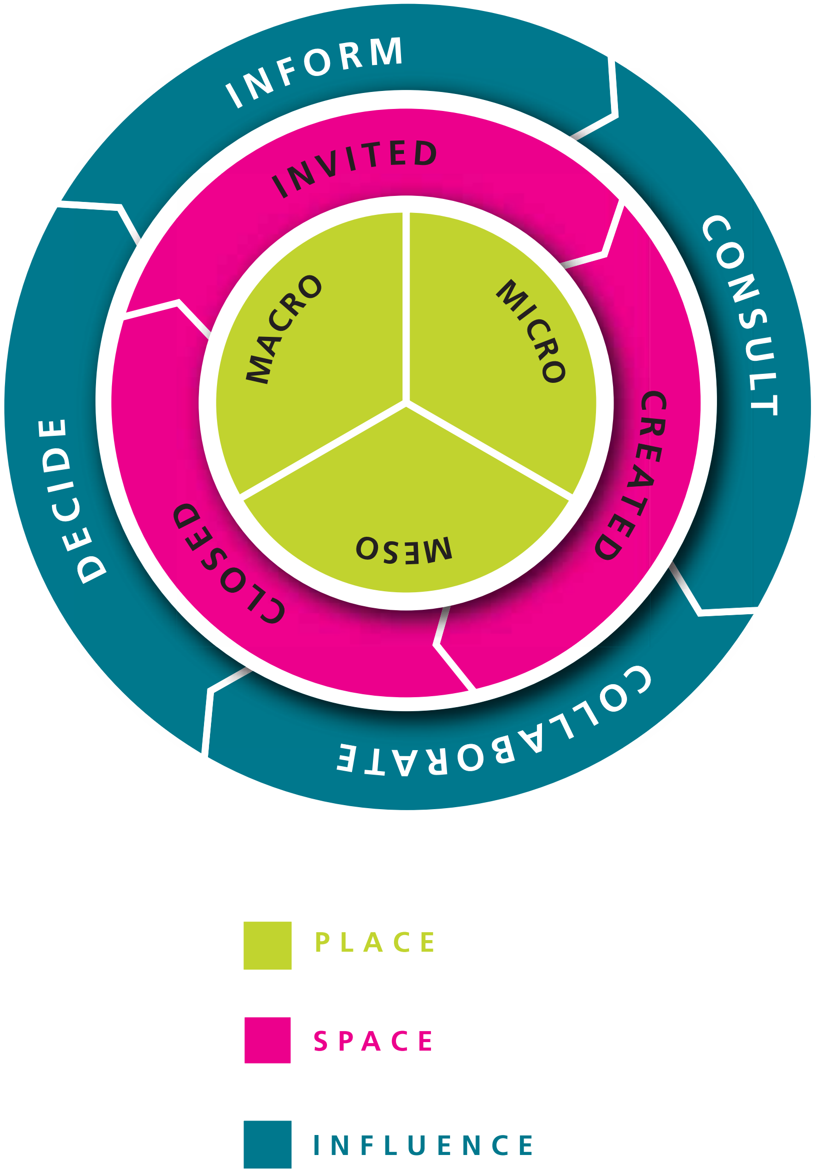
The Power Wheel



DIMENSION	Level as applied to patient engagement
PLACE: A socially-constructed arena where social, political and economic power is held. Place directs the levels on which agents can exert influence and each level is interrelated to the others.	**MICRO:** The healthcare system project (clinical practice, policy or research) which is the reason for patient engagement.
	MESO: The institutions where patient engagement occurs and the funding bodies responsible for resource-allocation (i.e., hospitals, ministries, governing bodies, industry, granting agencies).
	MACRO: The jurisdictions where high-level decisions are taken affecting health and social systems which influence patient engagement activities.
SPACE: A physical or abstract setting that has been shaped by social and cultural forces where interactions take place between agents and actors. Space is typically confined within the ideological possibilities of the actors who create the space.	**CLOSED:** Healthcare spaces where decision-making occurs without patient and public involvement.
	INVITED: Healthcare spaces where patient partner perspectives on a predetermined topic or area of study are solicited.
	CREATED: Informal or formal spaces where patients collect and gather around a common need, creating their own boundaries around priorities, policies and programs.
INFLUENCE: Also understood as social power, in which a social relation between two individuals is able to influence an outcome such as a decision.	**INFORM:** Patients are provided information about what is being done and what it means for them. Patients have no influence on the outcome.
	CONSULT: Patients are involved in providing feedback and input on a specific project. Patient input is taken into consideration when decisions are made.
	COLLABORATE: Patients work together with decision-makers to develop alternatives. Decisions are made together with patients.
	DECIDE: Patients prioritise and decide what is relevant and important. Decisions are made by patients and implemented by institutions and project teams.

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Declarations

Ethics approval

No ethics approval was needed for this commentary as no data was collected or analysed to inform the manuscript.

Authors' contributions

Ambreen Sayani, Emily Cordeaux, Omar Khan and Alies Maybee contributed to the manuscript conception and design. The first draft of the manuscript was written by Ambreen Sayani. Emily Cordeaux, Kelly Wu, Fatah Awil, Victoria Garcia, Ryan Hinds, Tara Jeji, Omar Khan, Bee Lee, Alies Maybee, Desiree Mensah, Linda Monteith, Mursal Musawi, Marlene Rathbone, Jill Robinson, Ambreen Sayani, Staceyan Sterling, Dean Wardak, Isra Amsdr, Mohadessa Khawari, Salve Niwe, Azmina Hussain, Victoria Forster commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Patient partner, Marlene Rathbone passed away in July 2023. Her legacy and wisdom are deeply entrenched into the values and mission of EMPaCT. Marlene's message was simple, "Be kind, be compassionate and just listen."

Introduction

Health systems are increasingly recognising the importance of actively involving patients in decision-making to achieve the Quintuple Aim, the Institute of Healthcare Improvement's framework for improving patient experience, population health, work-life of healthcare providers, reducing costs, and promoting equity (1). The Canadian Institutes of Health Research (the Canadian federal health funding agency), uses the term "patient " to describe a person with experience of a healthcare issue – including caregivers, families and friends (2). In this context, patient partner is a term used to describe a variety of decision-making roles held by patients that encompass clinical practice, policy and research. This occurs through a process known as patient engagement, where patient partners and health system partners (people in the healthcare system who engage with patient partners for clinical practice, research or policy) collaborate to design care to meet patient needs, enhance the relevance and impact of care and optimize cost-effectiveness (3,4). We recognize that the term patient partner is not without limitations, and that other jurisdictions may use different terms such as patient advisors, patient experience advisors, health consumers, patient advocates, or persons with lived experience (5,6) to describe similar roles. This exploration is beyond the scope of this article – and we adopt the Canadian terminology of patient partner and focus on patient engagement as it relates to the involvement of patients in health system decision-making (not their own direct care). While we acknowledge the growing number of studies and frameworks on co-production in healthcare policy and research(7–9), their remains a dearth of literature on power relations in patient engagement – particularly as it relates to partnering with diverse individuals and equitable involvement in decision-making. To fill this knowledge gap, we draw on theoretical concepts of power and our own experiences in patient engagement. Specifically, we introduce readers to a new conceptual tool to unpack and understand issues of power as they relate to patient engagement and equity, diversity and inclusion (EDI). We build on Gaventa's conceptualization of the power cube to create a **Power Wheel** that can be used to analyse the interspersion of power in the places and spaces of patient engagement. Our aim is to leave readers with a tool to help illuminate opportunities for equitable transformation and social inclusion so that health services can meet the needs and priorities of all people.

The issue: Exclusionary practices and the need for inclusive patient engagement

A significant challenge in promoting health equity through patient engagement is ensuring diverse perspectives are included in decision-making (10). In particular, engagement with individuals experiencing marginalizing societal conditions created through historical and systemic discrimination (i.e., low income, low literacy level and/or lack of fluency in the dominant language, gender, sexual orientation, racialization, Indigenous identity and ancestry, disability and housing insecurity or homelessness) (11) is a crucial step in developing inclusive services and policies that promote equitable access to health care and better health outcomes for all. A failure to do this leads to perpetuation of the status quo, further marginalization of individuals experiencing societal disadvantage and a widening of health inequities.

Exclusionary patient engagement can occur due to a lack of material resources, prohibitive institutional practices (12) and engagement processes that are not inclusive in design (13). For instance, diverse and structurally underserved patients tend to be underrepresented through ***institutional patient engagement models*** (see glossary of terms) such as Patient and Family

Advisory Councils (PFACs) or patient partner rosters, engagement models that are frequently employed by healthcare organizations seeking to solicit patient perspectives. This is in part because diverse and structurally underserved patients are less likely to hold prior relationships with institutions because of historical trauma, stigma or discrimination (11). These roles are also often volunteer positions, making them inaccessible to individuals who cannot afford to participate without compensation. Furthermore, meetings tend to occur at times and places that meet the schedules of health system partners rather than the preferences of patient partners. As a result, institutional patient engagement tends to primarily involve individuals possessing the necessary resources, connections and familiarity with the health system. For example, a recent Canadian survey found that most patient partners are female, white, university-educated and born in Canada (5). This underscores the lack of diversity among patient partners and demonstrates how ***social inequities*** shaped by access to material, social and cultural capital maintain exclusion and can reinforce the status quo leading to entrenched ***social structural inequities*** (see glossary of terms below) (10,11,14).

A solution: Equity Mobilizing Partnerships in Community (EMPaCT)

Equity Mobilizing Partnerships in Community (EMPaCT) is an award-winning, scalable model of diverse and inclusive patient engagement co-created in direct response to exclusionary patient engagement practices. EMPaCT was co-designed by developing five key principles for building inclusive and diverse patient partnerships (11) (Table 1) and collectively imagining what a new model of patient engagement would look like if all these principles were applied in practice. In doing so, we co-designed a disruptive innovation – a co-governed and collaborative ***community table model*** of patient engagement centered around improving health equity (10).

Five key principles
1. Use an equity-oriented approach
2. Co-build sustainable safe spaces
3. Address issues of accessibility
4. Build capacity one relationship at a time
5. Do no harm

Table 1: Five key principles for building inclusive and diverse patient partnerships (adapted with permission from Ambreen Sayani).

As a ***community table model*** (see glossary of terms), EMPaCT is equity-oriented (engaging with those least likely to be included with the greatest amount of outreach); trauma-informed (nurturing relationships of trust that recognize structures and systems of oppression and power imbalance); and sustainable (engagement is relationship-based and not bound to the lifecycle or funding of a specific project) (10,11). Members of EMPaCT co-designed how, why and when they wanted to be engaged in projects. They co-developed a process to translate their collective lived experiences into a Health Equity Analysis (HEA) for decision-makers. Decision-makers (such as policymakers, researchers and clinicians) request a seat at the EMPaCT community table, flipping power dynamics such that patient partners decide who they will engage with, the time and place of engagement, appropriate compensation for their expertise, and accountability structures for decision-makers who engage with them. Individuals on the table have a safe space within which to share insights and influence recommendations giving them a power not usually available to them within other models of engagement.

Learning from EMPaCT

EMPaCT was co-initiated in 2020 by a patient partner (Alies Maybee) and scientific partner (Ambreen Sayani). Since then, our community table has organically grown and currently comprises 20 members. These include 14 patient partners, (Alies Maybee, Isra Amsdr, Fatah Awil, Tara Jeji, Omar Khan, Mohaddesa Khawari, Bee Lee, Desiree Mensah, Linda Monteith, Mursal Musawi, Jill Robinson, Staceyan Sterling, Dean Wardak, Victoria Garcia) who represent a diversity of intersectional social identities; two community partners, defined as individuals who volunteer their time to support community outreach and engagement (Ryan Hinds, Kelly Wu); three academic trainees, defined as individuals who work under supervision to enhance their research and patient engagement skills (Emily Cordeaux, Salva Niwe, Azmina Hussain); and a scientific lead, responsible for leading the intellectual direction of proposed activities and coordinating the financial and administrative aspects of grants and awards (Ambreen Sayani). This paper stems from over 30 years of collective experience as patient partners involved across the healthcare ecosystem (including patient partner, Victoria Forster who is also a scientist) and the experience of health system partners with experience engaging diverse communities (Cordeaux, Wu, Niwe, Hinds, Hussain and Sayani). Sayani is a health system leader, physician and critical social scientist, who studies inclusive patient engagement and health equity. We are all co-authors on this paper.

EMPaCT meets monthly, and over time we have increasingly reflected on how power is shared within our group, and with health system partners who engage with the table. We have reflected on how these power dynamics contrast with other models, such as the institutional model of patient engagement. ***We collectively identify power relations as a key barrier to equity-oriented patient engagement***. In this next section, we explore how concepts of power relate to patient engagement and issues of EDI. Inspired by Gaventa's conceptualisation of the power cube, we then introduce the ***Power Wheel***, a tool to better understand and transform spaces and places of patient engagement so that they can become more diverse, inclusive and equitable aligning with the goals of the Quintuple Aim. Finally, we share how our group uses the ***Power Wheel*** to inform its work and leave readers with reflective prompts to interrogate power in the spaces and places of patient engagement.

Concepts of power as they relate to patient engagement and EDI

Power dynamics within engagement practices and between social relations remains an underexplored area in patient engagement. Power can be understood as the ability (agency) of an individual (agent) to act. In the literature on power relations, the ability of an agent to create an outcome is described as 'power to'; and the concept of 'power over' refers to the asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other. In contrast, 'power with' is the ability of a group to act and mobilize together towards a collective outcome (15–17). Power is mediated through social relations and legitimized through social practices such as language, policies and the production of knowledge (18,19).

In the context of patient engagement, power relates to the ability (agency) of patient partners (agents) to influence the outcome of decision-makers (actors) in the healthcare ecosystem. In patient engagement, power differentials are commonplace, as patient partners are often not involved in priority setting or direct decision-making. This leads to tokenistic patient engagement practices, where patient partner perspectives are not listened to or reflected in decision-making (20–22). In the context of diverse patient engagement, power influences who can participate in decision-making; and determines the degree to which decisions are inclusive of diverse perspectives towards a goal of improving health equity. ‘Power to’ in patient engagement is the ability of patient partners to engage in healthcare decision-making; and when applying an equity lens, means the ability of diverse individuals to be included as patient partners in decisions. ‘Power over’ is the ability or degree to which patient partners can influence decision-making to improve healthcare; and through an EDI lens is the degree to which diverse patient partners inform decisions. Finally, ‘power with’ is the ability of patient partners to be equal partners in decision-making; and through an EDI lens is the degree to which diverse patient partners are equal partners in decisions. Reflecting on power in patient engagement is important for increasing patient power influence broadly; and critical when seeking to improve EDI in patient engagement.

The Power Wheel

The Power Wheel is a tool that can be used to interrogate power relations in patient engagement, and promote learning, reflection, and transformative action so that places and spaces of patient engagement can become more inclusive of, and accessible to, diverse patient partners with a goal of improving health equity. The Power Wheel is an adaptation of the power cube, a concept first published in 2005 by John Gaventa as he reflected on citizen engagement and governance in the field of international development(23). Gaventa was concerned with the spaces of engagement, the places and levels at which citizen engagement was occurring and the interspersion of power within these dimensions (23). When considered together, these elements take the shape of a Power Cube – a framework which facilitates analysis of the dimensions of space, level and forms of power, and the interrelationship between each. While the power cube has been used to conduct power analyses in a variety of different settings(24) to our understanding, we are the first to adapt it to the field of patient engagement as a Power Wheel.

The Power Wheel (Figure 1) consists of three dimensions (***place, space and influence***) and each dimension has different levels through which power can be understood, configured and reconfigured through ongoing reflection and analysis. ***Places*** are socially constructed areas that have acquired meaning through human activities and interactions – and are areas where social, political and economic power are held. Places of patient engagement occur at the micro level, such as a healthcare system project that is the reason for patient engagement; the meso level, institutions where patient engagement occurs and the macro level, the jurisdictional levels at which health and social system decisions are made which impact patient engagement. The place of a patient engagement activity directs the levels where agents can exert influence, with each level interrelated to the others. ***Space*** refers to an abstract or physical setting where social interactions and relationships occur. Social and cultural forces determine the dimensions of space and can take three forms: closed, where decision-making occurs without patient engagement; invited, where patient partners are invited into healthcare spaces to contribute their perspectives on a predetermined topic or area of study; and created, informal or formal places where patient partners come together around a common need, and create their own boundaries around priorities, policies, and programs. Finally, ***influence*** is social power where a social relation between two or more individuals impacts an outcome such as a decision. Influence can take four forms in patient engagement activities: inform, where patient partners are merely provided with information about what is being done and what it means for them, and do not influence outcomes; consult, where patient partners are involved in providing feedback and input on a specific project; collaborate where their input is taken into account when decisions are made; and decide, where patient partners prioritise and decide what is relevant and important, and decisions are made by patient partners and implemented by institutions and projects. In summary, place determines which level of decision-making is open for discussion; space determines the social relationships between people that shape conversations around decision-making; and finally influence, is the degree to which decision-making is shared towards a common goal.

INSERT: Figure 1: The Power Wheel

Using the Power Wheel to analyse power in places and spaces of patient engagement

The Power Wheel can be used to interrogate power relations and to identify tangible opportunities for inclusive decision-making in patient engagement. In EMPaCT we use the Power Wheel to interrogate power relations in our internal group activities and our external decision-making influence. For example, as we continue to grow as a group – both in numbers and in terms of awards, opportunities and the breadth of our work, we are cognizant that we wield power differently now versus when we started. In 2021, we were primarily collaborating on micro-level projects within the institution where we are based, and as our expertise grew and we gained traction, we began making decisions for meso-level projects across the country. Currently, we are engaged in decisions that directly influence the outcomes of projects at a macro level. Thus, EMPaCT, as an organic, co-designed, ***community-table model of patient engagement*** is a co-created safe space, for micro, meso and macro-level transformative decision-making and influence. Based on our own experiences, EMPaCT sits in contrast to ***institutional models of patient engagement*** – which are primarily micro-level places, within which the invited spaces are most accessible to patient partners with higher levels of social, cultural and material capital who are ultimately involved in influencing decisions based on their own level of individual agency. We are conducting a case study of power relations in different models of patient engagement using the Power Wheel. This work is forthcoming.

We encourage researchers, clinicians, and decision-makers in health systems to use the **Power Wheel** as a **reflective tool** to analyse the various dimensions of power within their patient engagement practices; and as a **transformative tool** to identify tangible actions to modify spaces and places of patient engagement so they become more equitable in alignment with the goals of the Quintuple Aim. We urge readers to identify which opportunities exist or can be created to share power within their own patient engagement practices. In doing so, individuals who have been harmed and/or structurally excluded will have opportunities to safely influence decisions that affect their own health and well-being.

We leave readers with self-directed prompts to use with the Power Wheel to help interrogate power in the places and spaces of their patient engagement practices:

1. In what place(s) is your patient engagement work occurring?
2. Are these space(s) closed, open, or created?
3. What level of influence do patient partners have?

4. How could these factors influence the diversity of patient partners you are engaging?
5. How could your patient engagement practices be modified so that they are more inclusive?

Taking action to promote EDI in patient engagement

There are multiple ways to address EDI in patient engagement. This paper addresses one of the most important ones – the inclusion of diverse patient partners in decision making so that the needs and priorities of more people can be met. This is a key step towards improving health equity through the health system. The opposite of this, designing care with and for only people with privilege can perpetuate the status quo, further marginalizing groups that have been excluded, and amplify harms and inequities. We must take every effort to avert this scenario.

We recognise that most often, patient engagement activities have little to no influence on the determinants of oppression and exclusion. Similarly, the Power Wheel is also limited in its ability to conceptualize the political and economic inequities that create social structural exclusion. However, there are ways for health system partners to engage in bottom-up action through authentic, meaningful and diverse patient engagement, which can in turn create avenues for collective dialogue and policy-influence. It is only by accruing power back to individuals from structurally seldom-heard communities that we can begin to advance equity. When used as a tool for ongoing reflection and dynamic action, the Power Wheel enables us to rethink and redesign spaces and places of patient engagement to promote equity. We believe that the practice of equity-oriented patient engagement is a pursuit of social justice. We invite researchers, clinicians, and decision-makers to commit to addressing power inequities in spaces and places of patient engagement so that everyone can be involved in crafting priorities and influencing decisions that will lead to the betterment of our collective lives.

Glossary of terms used:

- **Social inequity:** Describes the unequal distribution of power, privilege and prestige across a society. Individuals who occupy positions of social advantage by virtue of their personal wealth and credentials are more able to access resources and services thereby creating further differentiation between social groups.
- **Social structural inequity:** Refers to the hierarchical ordering of people based on their position in society that is determined by their level of power, prestige and privilege. When social inequality becomes systematically entrenched in a society such that it is institutionalized into policies and procedures that continue to differentiate between social groups, it is called social structural inequality or social stratification.
- **Institutional patient engagement:** The engagement of patient partners in settings that are initiated, managed and maintained by institutions and groups in the health system.
- **Community table patient engagement:** A collectively governed and independent table of patient partners united by a shared purpose, value or identity. The model emphasizes inclusivity, equity and shared decision-making by creating a safe and accessible space for diverse people and communities.

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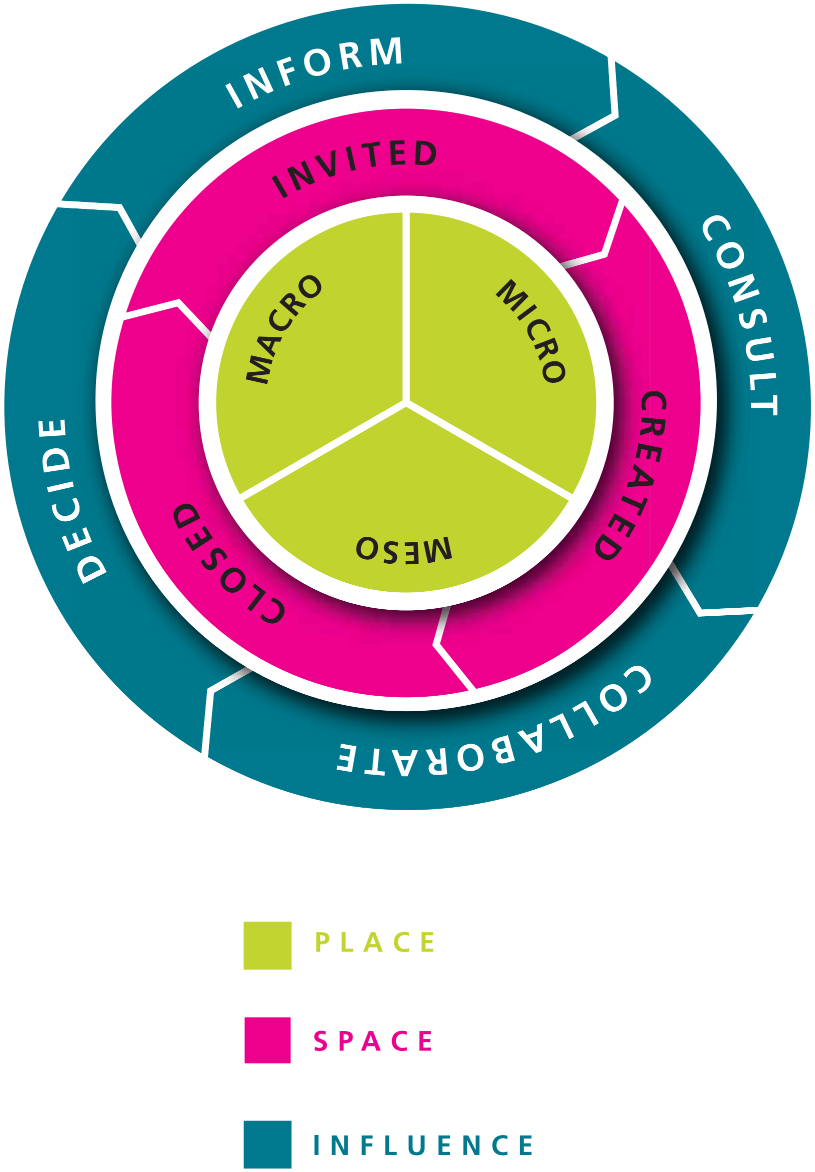
The Power Wheel



DIMENSION	Level as applied to patient engagement
PLACE: A socially constructed area that has acquired meaning through human activities and interactions and where social, political and economic power is held. Place directs the levels on which agents can exert influence and each level is interrelated to the others.	**MICRO:** The healthcare system project (clinical practice, policy development or research) which is the reason for patient engagement.
	MESO: The health and social institutions where patient engagement occurs (including healthcare and higher education institutions).
	MACRO: The jurisdictional levels at which health and social system decisions are made which impact patient engagement (including funding bodies that determine resource allocation).
SPACE: An abstract or physical setting where social interactions and relationships occur between agents and actors. Space is typically confined within the ideological possibilities of the actors who create the space.	**CLOSED:** Healthcare spaces where decision-making occurs without patient engagement.
	INVITED: Healthcare spaces where patient partner perspectives on a predetermined topic or area of study are solicited.
	CREATED: Informal or formal spaces where patient partners collect and gather around a common need, creating their own boundaries around priorities, policies and programs.
INFLUENCE: Also understood as social power, in which a social relation between two individuals is able to impact an outcome such as a decision.	**INFORM:** Patient partners are provided information about what is being done and what it means for them. Patient partners have no influence on the outcome.
	CONSULT: Patient partners are involved in providing feedback and input on a specific project. Patient partner input is taken into consideration when decisions are made.
	COLLABORATE: Patient partners work together with decision-makers to develop alternatives. Decisions are made together with patient partners.
	DECIDE: Patient partners prioritise and decide what is relevant and important. Decisions are made by patient partners and implemented by institutions and project teams.

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Using the Power Wheel as a transformative tool to promote equity through spaces and places of patient engagement.

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Abstract

Patient engagement is the active collaboration between patient partners and health system partners towards a goal of making decisions that centre patient needs – thus improving experiences of care, and overall effectiveness of health services in alignment with the Quintuple Aim. An important but challenging aspect of patient engagement is including diverse perspectives particularly those experiencing health inequities. When such populations are excluded from decision-making in health policy, practice and research we risk creating a healthcare ecosystem that reinforces structural marginalization and perpetuates health inequities. Despite the growing body of literature on knowledge co-production, few have addressed the role of power relations in patient engagement and offered actionable steps for engaging diverse patients in an inclusive way with a goal of improving health equity. To fill this knowledge gap, we draw on theoretical concepts of power, our own experience co-designing a novel model of patient engagement that is equity-promoting, Equity Mobilizing Partnerships in Community (EMPaCT), and over 30 years of collective experience as patient partners engaged across the healthcare ecosystem. We introduce readers to a new conceptual tool, the Power Wheel, that can be used to analyse the interspersion of power in the places and spaces of patient engagement. As a tool for ongoing praxis (reflection + action) the Power Wheel can be used to report, reflect and resolve power asymmetries in patient partnered projects, thereby increasing transparency and illuminating opportunities for equitable transformation and social inclusion so that health services can meet the needs and priorities of all people.

Declarations

Ethics approval

No ethics approval was needed for this commentary as no data was collected or analysed to inform the manuscript.

Authors' contributions

Ambreen Sayani, Emily Cordeaux, Omar Khan and Alies Maybee contributed to the manuscript conception and design. The first draft of the manuscript was written by Ambreen Sayani. Emily Cordeaux, Kelly Wu, Fatah Awil, Victoria Garcia, Ryan Hinds, Tara Jeji, Omar Khan, Bee Lee, Alies Maybee, Desiree Mensah, Linda Monteith, Mursal Musawi, Marlene Rathbone, Jill Robinson, Ambreen Sayani, Staceyan Sterling, Dean Wardak, Isra Amsdr, Mohadessa Khawari, Salve Niwe, Azmina Hussain, Victoria Forster commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Competing interests

AS is a recipient of the Transition to Leadership Stream Career Development Award in Patient-Oriented Research from the Canadian Institutes for Health Research and is a Health Equity Expert Advisor to the Canadian Partnership Against Cancer (CPAC). All other authors declare no competing interests.

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Patient partner, Marlene Rathbone passed away in July 2023. Her legacy and wisdom are deeply entrenched into the values and mission of EMPaCT. Marlene's message was simple, "Be kind, be compassionate and just listen."

Introduction

Patient engagement is the active collaboration between ***patient partners*** and ***health system partners*** across various decision-making roles in the healthcare ecosystem that include clinical practice, policy and research (1). When ***patients*** are partnered in these roles, they can design services and policies to centre their needs, enhance the relevance and impact of care and optimize cost-effectiveness in alignment with the Quintuple Aim (2–4). In this article, we use the term 'patient partner' to encompass all roles where patients and caregivers are involved in health system decision-making. Other common terms include patient advisors, patient experience advisors, health consumers, patient advocates and persons with lived/living experience (PWLLE) (5,6).

A significant challenge in promoting health equity through patient engagement is ensuring diverse perspectives are included in decision-making (7). In particular, engagement with individuals experiencing marginalizing societal conditions created through historical and systemic discrimination (i.e., low income, low literacy level and/or lack of fluency in the dominant language, gender, sexual orientation, racialization, Indigenous identity and ancestry, disability and housing insecurity or homelessness) (8) is a crucial step in developing inclusive services and policies that promote access to health care and equitable health outcomes**.** When we use the term 'diverse', we are broadly referring to perspectives that have not been included or represented in decision-making. When health system decisions are made without the input of diverse people experiencing inequities, services and policies continue to perpetuate the status quo leading to further exclusion, entrenched marginalization and a widening of health inequities.

Exclusionary patient engagement can occur due to a lack of material resources, prohibitive institutional practices (9) and engagement processes that are not inclusive in design (10). For instance, diverse and structurally marginalized patients tend to be underrepresented through ***institutional patient engagement models*** such as Patient and Family Advisory Councils (PFACs) or patient partner rosters, engagement models frequently employed by healthcare organisations seeking to solicit patient perspectives. This is in part because structurally marginalized patients are less likely to hold prior relationships with institutions due to historical trauma and experiences of stigma or discrimination in healthcare settings (8). Further to this, patient partner roles in the institutional patient engagement model are often volunteer positions, making them inaccessible to individuals who cannot afford to participate without compensation. Meetings also tend to occur at times and places that meet the schedules of health system partners rather than the preferences of patient partners. As a result, institutional patient engagement tends to primarily involve individuals possessing the necessary resources, connections and familiarity with the health system. This was reflected in a recent Canadian survey which found that most patient partners are women, white, university-educated, older and born in Canada (5). This underscores the lack of diversity among patient partners and demonstrates how ***social inequities*** shaped by access to material, social and cultural resources leads to stratification among patient partners based on their degree of privilege and can contribute to ***social structural inequities*** (7,8,11).

Populations experiencing the most health inequities are embedded in a structural web of exclusion from policymaking and research practices. These exclusions must be redressed if we are to improve the health of all people. In the context of patient engagement, fair and just health outcomes can be achieved if structurally marginalized patient partners have the ***power*** to be involved in decision-making and the ***influence*** to steer outcomes towards a goal of improving health equity. Despite the growing number of studies and frameworks on co-production in healthcare policy and research (12–14) there is a dearth of literature on power relations in patient engagement and few actionable tools to support praxis (reflection + action) – particularly as it relates to partnering with diverse individuals and equitable involvement in decision-making. To fill this knowledge gap, we draw on theoretical concepts of power, our own experience co-designing a novel model of patient engagement that is equity-promoting, Equity Mobilizing Partnerships in Community (EMPaCT), and over 30 years of collective experience as patient partners engaged across the healthcare ecosystem. We introduce readers to a new conceptual tool that can be used to unpack, understand and report on issues of power as they relate to patient engagement and equity. In doing so, we build on Gaventa's conceptualisation of the power cube to create a **Power Wheel** that can be used to analyse the interspersion of power in the places and spaces of patient engagement. Our aim is to leave readers with a tool to help illuminate opportunities for equitable transformation and social inclusion so that health services can better meet the needs and priorities of all people.

Concepts of power as they relate to patient engagement and equity

Power can be understood as the ability (agency) of an individual (agent) to act. In the literature on power relations, the ability of an agent to create an outcome is described as ***power to***; and the concept of ***power over*** refers to the asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other. In contrast, ***power with*** is the ability of a group to act and mobilise together towards a collective outcome (15–17). Power is mediated through social relations and legitimised through social practices such as language, policies and the production of knowledge (18,19).

In the context of patient engagement, power relates to the ability (agency) of patient partners (agents) to influence the outcome of decision-makers (actors) in the healthcare ecosystem. In patient engagement, power differentials are commonplace, as patient partners are often not involved in priority setting or direct decision-making. This leads to tokenistic patient engagement practices, where patient partner perspectives are not listened to or included in decision-making (20–22). In the context of diverse patient engagement, power influences who can participate in decision-making and the degree to which decisions are inclusive of diverse perspectives towards a goal of improving health equity. We define 'power to' in patient engagement as the ability of patient partners to engage in health system decision-making. When applying an equity lens, 'power to' means the ability of people who experience marginalizing social conditions to be included as patient partners in decisions. 'Power over' is the ability or degree to which patient partners can influence decision-making to improve health outcomes; and through an equity lens is the degree to which diverse patient partners can impact decisions that will advance their health. Finally, we define 'power with' as the ability of patient partners to group together for a collective goal of improving health outcomes; and through an equity lens is the ability of diverse patient partners to independently mobilise and influence health system decision-making.

It is important to note that populations who experience structural marginalization are less likely to have the material, social and cultural resources to be involved and influential as patient partners. Consequently, the range of patient engagement opportunities differs significantly between social groups, such that those who are more privileged wield more decision-making power and influence than those who are not – resulting in policies and services that are centered around the needs of those who already have better health. An alternative scenario to this, is to centre decision-making around the needs of the most structurally marginalized, in a concept known as ***centering the margins*** (23). From this point of view, policies and services that meet the needs of those experiencing the most health inequities are the most inclusive, and thus, will improve health outcomes for all people regardless of their degree of privilege. To centre the margins, power must be shared with structurally marginalized communities and processes of accountability must be created so that lived experiences directly influence equity-oriented decision-making.

Learning from an innovation in equity-promoting patient engagement: EMPaCT

Equity Mobilizing Partnerships in Community (EMPaCT) is an example of a scalable model of diverse and inclusive patient engagement co-created in direct response to exclusionary patient engagement practices. EMPaCT was co-designed by developing five key principles for building inclusive and diverse patient partnerships (8) (Table 1) and collectively imagining what a new model of patient engagement would look like if all these principles were applied in practice. In doing so, members of EMPaCT co-designed how, why and when they wanted to be engaged in projects by co-designing processes that are (7,8):

1. **Equity-oriented**: engaging with those least likely to be included with the greatest amount of outreach;
2. **Trauma-informed**: nurturing relationships of trust that recognise structures and systems of oppression and power imbalance; and
3. **Sustainable**: engagement spaces that are relationship-based and not bound to the lifecycle or funding of a specific project.

To increase their capacity to influence decision-makers, EMPaCT co-developed a process to translate the collective lived experiences of members into a written Health Equity Analysis (HEA) (paper forthcoming). Decision-makers (such as policymakers, researchers and clinicians) who seek a HEA request a seat at the EMPaCT community table, flipping power dynamics such that patient partners decide who they will engage with, the time and place of engagement, appropriate compensation for their expertise, and accountability structures for decision-makers who engage with them. Individuals on the table have a safe relationship-based space within which to share insights and influence recommendations, accruing power in ways not usually possible within other engagement models.

Five key principles for equity-promoting patient engagement
1. Use an equity-oriented approach
2. Co-build sustainable safe spaces
3. Address issues of accessibility
4. Build capacity one relationship at a time
5. Do no harm

Table 1: Five key principles for building inclusive and diverse patient partnerships (adapted with permission from Ambreen Sayani).

Reflecting a ***community table model of patient engagement***, EMPaCT is a co-governed model of patient engagement that exemplifies how power can be shared between health system partners and patient partners towards a goal of improving health equity (7). As a group, we have increasingly discussed how power is shared both within our group, and with health system partners who engage with the table. We have reflected on how these power dynamics contrast with other models, such as the institutional model of patient engagement. **We collectively identify asymmetric power relations as a key barrier to equity-oriented patient engagement**. Inspired by Gaventa's conceptualisation of the power cube, we have developed a ***Power Wheel*** tool to help others better understand how power relations operate in the spaces and places of patient engagement so that they can be transformed and aligned towards a goal of improving health equity.

The Power Wheel

The Power Wheel is a conceptual tool that can be used to interrogate power relations in patient engagement. As a tool it can promote learning, reflection and transformative action so that places and spaces of patient engagement can become more inclusive of, and accessible to, diverse patient partners with a goal of improving health equity. The Power Wheel is an adaptation of the power cube, a concept first published in 2005 by John Gaventa as he reflected on citizen engagement and governance in the field of international development (24). Gaventa was concerned with the spaces of engagement, the places and levels at which citizen engagement was occurring and the interspersion of power within these dimensions (24). When considered together, these elements take the shape of a Power Cube – a framework which facilitates analysis of the dimensions of space, level and forms of power, and the interrelationship between each. While the power cube has been used to conduct power analyses in a variety of different settings (25), to our understanding, we are the first to adapt it to the field of patient engagement as a Power Wheel.

The Power Wheel (Figure 1) consists of three dimensions (**place, space and influence**) and each dimension has different levels through which power can be understood, configured and reconfigured through ongoing reflection and analysis. **Place** is a socially constructed area that has acquired meaning through human activities and interactions. Places hold different degrees of social, political and economic power depending on their level: micro, meso or macro. Patient engagement activities frequently occur at an individual-project, or micro-level – where patient partner perspectives are sought for specific clinical practice, research or localised policy projects. Meso-level places have intermediate-level impact, and meso-level patient engagement can lead to changes in institutions, organisations, or specific communities. Large-scale, wide-ranging impacts through social, political and economic changes are possible through macro-level places. **Space** refers to an abstract or physical setting where social interactions and relationships occur. Social and cultural forces determine the dimensions of space and can take three forms: closed, where decision-making occurs without patient engagement; invited, where patient partners are invited into healthcare spaces to contribute their perspectives on a predetermined topic or area of study; and created, informal or formal places where patient partners come together around a common need, and create their own boundaries around priorities, policies and programs. Finally,

influence is social power where a social relation between two or more individuals determines an outcome such as a decision. Influence can take four forms in patient engagement activities: inform, where patient partners are merely provided with information about what is being done and what it means for them, and do not influence outcomes directly; consult, where patient partners are involved in providing feedback and input on a specific project; collaborate where their input is taken into account when decisions are made; and decide, where patient partners prioritise and decide what is relevant and important, and decisions are made by patient partners and implemented by institutions and projects.

In summary, place determines which level of decision-making is open for discussion; space determines the social relationships between people that shape conversations around decision-making; and finally, influence is the degree to which decision-making is shared towards a common goal.

INSERT: Figure 1: The Power Wheel

The Power Wheel can be used to analyse the interspersion of power in places and spaces of patient engagement. For example, in Figure 2, power is distributed at a micro-level, invited-space that is open for consultation-level influence. The wheel in Figure 2 can exemplify a variety of institutional patient engagement activities that have localized impact – such as a quality improvement project in a specific department. In Figure 3, power is distributed more broadly – with macro-level, collaborative decision-making, in a created space that was decided by patient partners. The wheel in Figure 3 is an example of a project where EMPaCT was engaged in national-level policymaking. As a community-table, EMPaCT is unique because members of EMPaCT decide which projects they want to engage with – and ultimately the engagement determines the degree of influence EMPaCT has on the outcomes of the project. Thus, EMPaCT always exerts multiple levels of influence, both determined by its novel model of patient engagement and the level of decision-making power available through a health system partner's project. We are conducting a case study of power relations in different models of patient engagement using the Power Wheel. This work is forthcoming.

INSERT: Figure 2: The Power Wheel: Institutional patient engagement for a localised quality improvement project

INSERT: Figure 3: The Power Wheel: EMPaCT engagement for a national-level policy

Using the Power Wheel to transform places and spaces of patient engagement

The Power Wheel is an action-oriented tool that supports better praxis in equity-promoting patient engagement. Researchers, clinicians and decision-makers in health systems can use the Power Wheel as a **reporting tool** to share their patient engagement practices**,** as a **reflective tool** to analyse the various dimensions of power within their patient engagement practices and as a **transformative tool** to identify tangible actions to modify spaces and places of patient engagement so they become more equitable in alignment with the goals of the Quintuple Aim.

We recommend using the Power Wheel to **report**, **reflect**, and **resolve** power asymmetries within patient engagement practices in the following ways:

1. **Report**: The current status of decision-making influence within a given patient engagement project can be reported as a figure in the methods section of presentations, reports and publications to promote transparency and accountability in patient engagement practices. We have given examples of how The Power Wheel can be used for reporting in Figures 2 and 3, and recommend that this becomes a component of regular reporting for all projects that include patient partners.
2. **Reflect**: The spaces and places of patient engagement within a given project can be analysed to question which perspectives are privileged in decision-making and which are absent. The diversity jigsaw is an activity that can be completed individually or as a group alongside the Power Wheel to unpack which identities, such as race, gender, class, sexual orientation, disability, etc. are currently included/ excluded and how issues of power asymmetry may be contributing to participation.
3. **Resolve**: The opportunities to transform power asymmetries can be identified and existing skills, knowledge, relationships and resources mobilized to promote health equity. This can be done using a strengths-based, relationship-driven approach to addressing challenges, fostering collaboration, and promoting inclusivity known as asset mapping.

Conclusion

We believe that the practice of equity-oriented patient engagement is a pursuit of social justice. It is only by accruing power back to individuals from structurally marginalized communities that we can begin to advance equity. While patient engagement activities often have little to no influence on the determinants of oppression and exclusion, meaningfully including diverse patient partners in decision making is a key step towards improving health equity through the health system. When used as a tool for reporting, ongoing reflection and dynamic action, the Power Wheel enables us to rethink and redesign spaces and places of patient engagement to promote equity. We invite researchers, clinicians, and decision-makers to commit to addressing power inequities in spaces and places of patient engagement so that everyone can be involved in crafting priorities and influencing decisions that will lead to the betterment of our collective lives.

Glossary of terms as they appear in text:

Term	Definition
Patient partner	A term used to describe a variety of decision-making roles held by patients that encompass clinical practice, policy and research.
Health system partner	People in the healthcare system who engage with patient partners for clinical practice, research or policy.
Patient	Describes a person with experience of a healthcare issue – including caregivers, families and friends (1).
Institutional patient engagement model	The engagement of patient partners in healthcare institutions where patient partner perspectives can influence decision-making and project outcomes, encompassing research and institutional policy and/or clinical practice.
Social inequities	Describes the unequal distribution of power, privilege and prestige across a society. Individuals who occupy positions of social advantage by virtue of their personal wealth and credentials

	are more able to access resources and services thereby creating further differentiation between social groups (11).
Social structural inequities	Refers to the hierarchical ordering of people based on their position in society that is determined by their level of power, prestige and privilege. When social inequality becomes systematically entrenched in a society such that it is institutionalized into policies and procedures that continue to differentiate between social groups, it is called social structural inequality or social stratification (11).
Power	The ability (agency) of an individual (an agent) to act. Power is mediated through social relations and legitimized through social processes such as language, policies and the production of knowledge .(15-19)
Influence	Social power where a social relation between two or more individuals determines an outcome such as a decision.
Power to	The ability of an agent to create an outcome (15–17).
Power over	The asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other (15–17).
Power with	The ability of a group to act and mobilise together towards a collective outcome (15–17).
Centering the margins	Centering decision-making around the needs of the most structurally marginalized (23).
Community table model of patient engagement	An independent table of patient partners united by a shared purpose, value or identity. The model emphasizes inclusivity, equity and shared decision-making by creating a safe and accessible space for diverse people and communities.
Power Wheel	A conceptual tool that can be used to analyse the interspersion of power in places and spaces of patient engagement.

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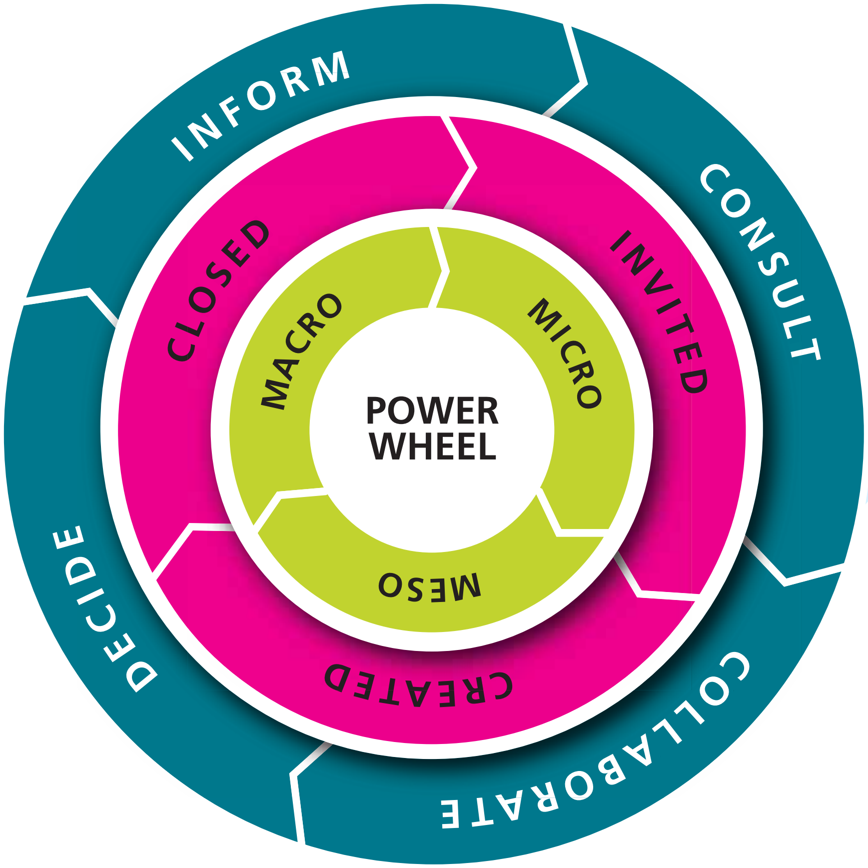
The Power Wheel



🟩 PLACE

🟥 SPACE

🟦 INFLUENCE

DIMENSION	LEVEL
PLACE: A socially constructed area that has acquired meaning through human activities and interactions and where social, political and economic power is held. Place directs the levels on which agents can exert influence and each level is interrelated to the others.	**MICRO:** Individual projects (clinical practice, research) or localised policy issues.
	MESO: Intermediate-level projects that lead to changes in institutions, organizations, or specific communities.
	MACRO: Large-scale social, economic or political issues that have a wide-ranging impact on society as a whole.
SPACE: An abstract or physical setting where social interactions and relationships occur between agents and actors. Space is typically confined within the ideological possibilities of the actors who create the space.	**CLOSED:** Healthcare spaces where decision-making occurs without patient engagement.
	INVITED: Healthcare spaces where patient partner perspectives on a predetermined topic or area of study are solicited.
	CREATED: Informal or formal spaces where patient partners collect and gather around a common need, creating their own boundaries around priorities, policies and programs.
INFLUENCE: Also understood as social power, in which a social relation between two individuals is able to impact an outcome such as a decision.	**INFORM:** Patient partners are provided information about what is being done and what it means for them. Patient partners have no influence on the outcome.
	CONSULT: Patient partners are involved in providing feedback and input on a specific project. Patient partner input is taken into consideration when decisions are made.
	COLLABORATE: Patient partners work together with decision-makers to develop alternatives. Decisions are made together with patient partners.
	DECIDE: Patient partners prioritise and decide what is relevant and important. Decisions are made by patient partners and implemented by institutions and project teams.

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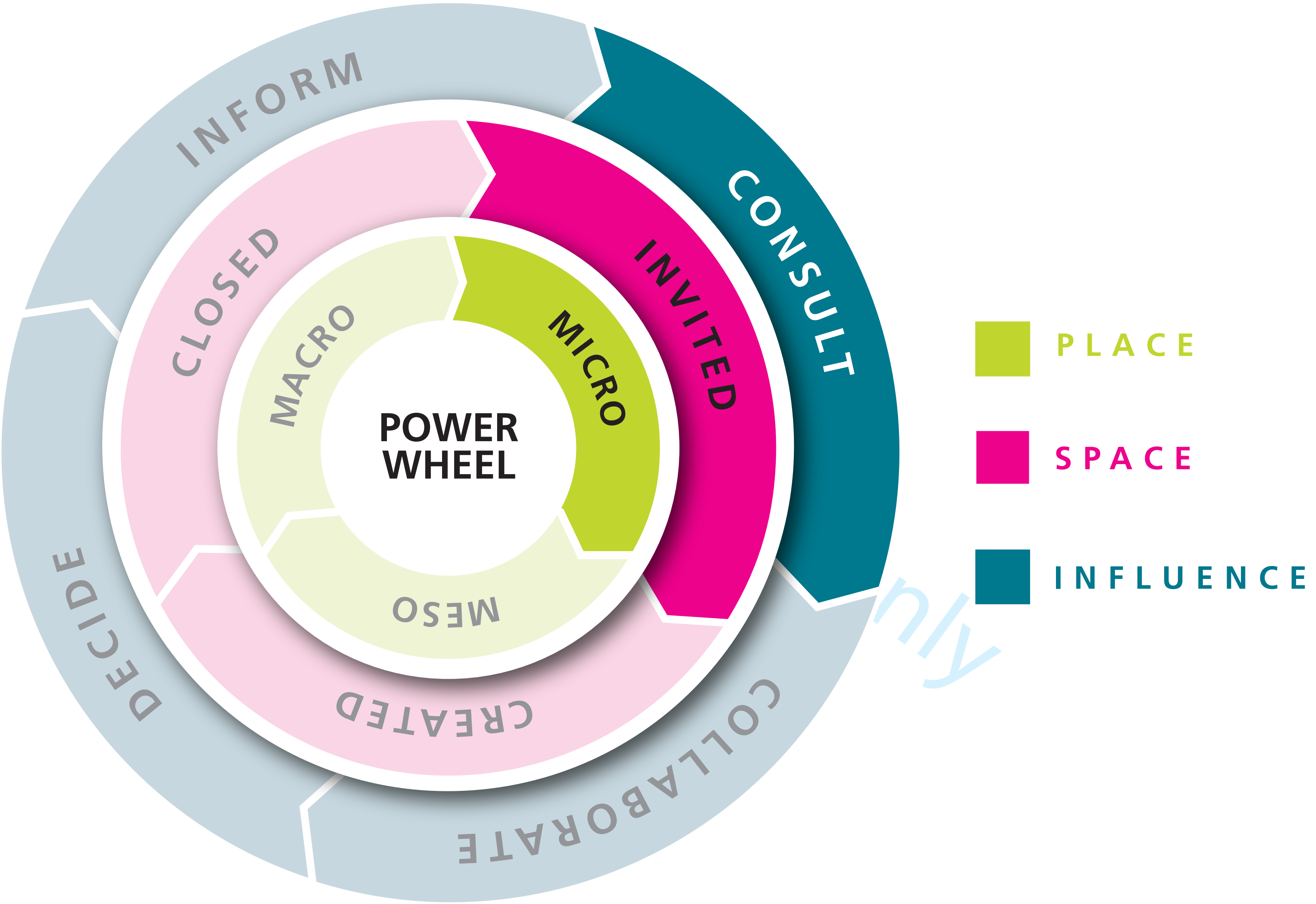
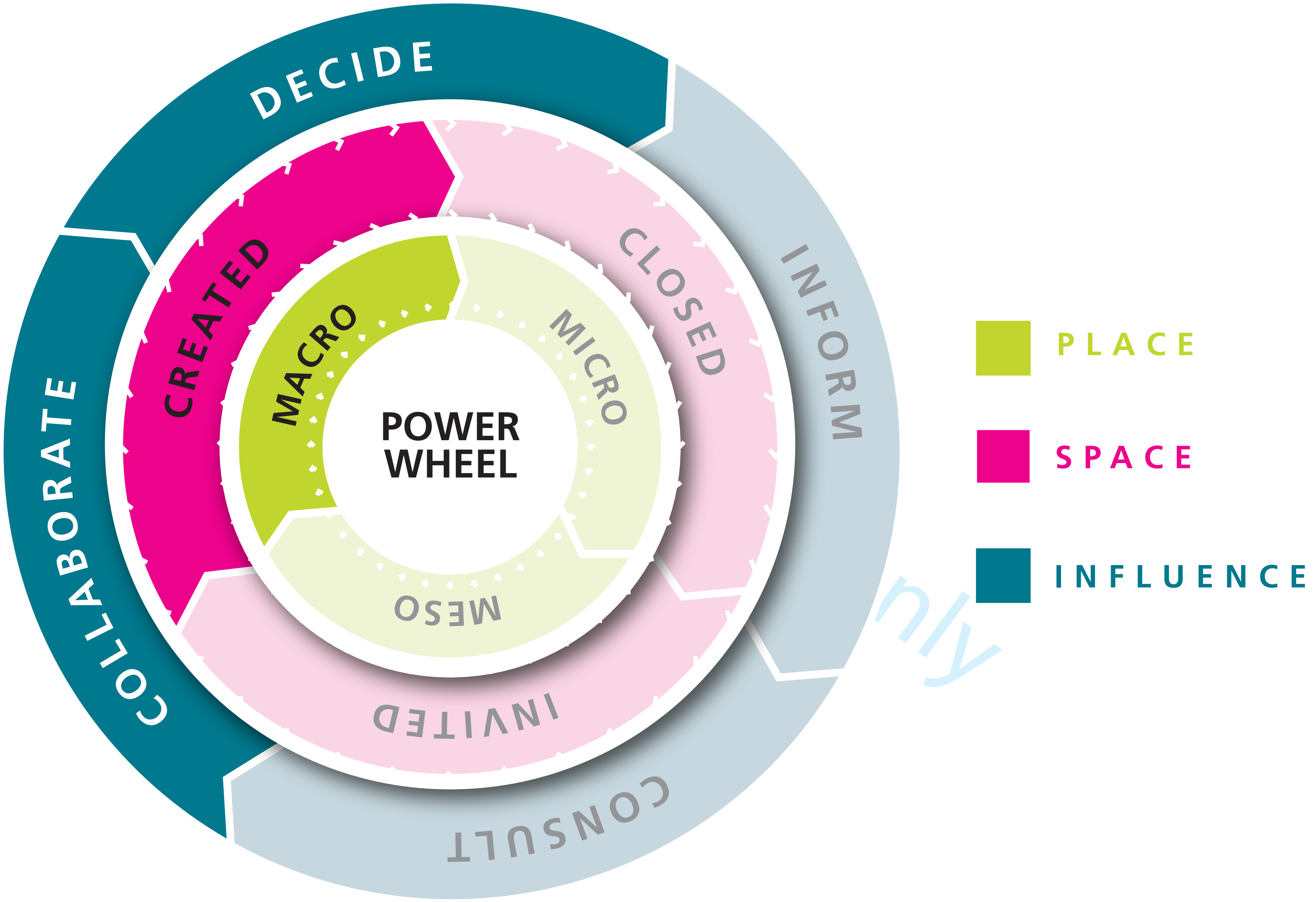
Institutional Patient Engagement

Quality improvement



Equity Mobilizing Partnerships in Community (EMPaCT)

Policy



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Using the Power Wheel as a transformative tool to promote equity through spaces and places of patient engagement

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Using the Power Wheel as a transformative tool to promote equity through spaces and places of patient engagement

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Abstract

Patient engagement is the active collaboration between patient partners and health system partners towards a goal of making decisions that centre patient needs – thus improving experiences of care, and overall effectiveness of health services in alignment with the Quintuple Aim. An important but challenging aspect of patient engagement is including diverse perspectives particularly those experiencing health inequities. When such populations are excluded from decision-making in health policy, practice and research we risk creating a healthcare ecosystem that reinforces structural marginalization and perpetuates health inequities. Despite the growing body of literature on knowledge co-production, few have addressed the role of power relations in patient engagement and offered actionable steps for engaging diverse patients in an inclusive way with a goal of improving health equity. To fill this knowledge gap, we draw on theoretical concepts of power, our own experience co-designing a novel model of patient engagement that is equity-promoting, Equity Mobilizing Partnerships in Community (EMPaCT), and extensive experience as patient partners engaged across the healthcare ecosystem. We introduce readers to a new conceptual tool, the Power Wheel, that can be used to analyse the interspersion of power in the places and spaces of patient engagement. As a tool for ongoing praxis (reflection + action) the Power Wheel can be used to report, reflect and resolve power asymmetries in patient partnered projects, thereby increasing transparency and illuminating opportunities for equitable transformation and social inclusion so that health services can meet the needs and priorities of all people.

Introduction

Patient engagement is the active collaboration between *patient partners* and *health system partners* across various decision-making roles in the healthcare ecosystem that include clinical practice, policy and research (1). When *patients* are partnered in these roles, they can design services and policies to centre their needs, enhance the relevance and impact of care and optimize cost-effectiveness in alignment with the Quintuple Aim (2–4). In this article, we use the term 'patient partner' to encompass all roles where patients and caregivers are involved in health system decision-making. Other common terms include patient advisors, patient experience advisors, health consumers, patient advocates and persons with lived/living experience (PWLLE) (5,6).

A significant challenge in promoting health equity through patient engagement is ensuring diverse perspectives are included in decision-making (7). In particular, engagement with individuals experiencing marginalizing societal conditions created through historical and systemic discrimination (i.e., low income, low literacy level and/or lack of fluency in the dominant language, gender, sexual orientation, racialization, Indigenous identity and ancestry, disability and housing insecurity or homelessness) (8) is a crucial step in developing inclusive services and policies that promote access to health care and equitable health outcomes**.** When health system decisions are made without the input of diverse people experiencing inequities, services and policies continue to perpetuate the status quo leading to further exclusion, entrenched marginalization and a widening of health inequities.

Exclusionary patient engagement can occur due to a lack of material resources, prohibitive institutional practices (9) and engagement processes that are not inclusive in design (10). For instance, diverse and structurally marginalized patients tend to be underrepresented through *institutional patient engagement models* such as Patient and Family Advisory Councils (PFACs) or patient partner rosters, engagement models frequently employed by healthcare organisations seeking to solicit patient perspectives. This is in part because structurally marginalized patients are less likely to hold prior relationships with institutions due to historical trauma and experiences of stigma or discrimination in healthcare settings (8). Further to this, patient partner roles in the institutional patient engagement model are often volunteer positions, making them inaccessible to individuals who cannot afford to participate without compensation. Meetings also tend to occur at times and places that meet the schedules of health system partners rather than the preferences of patient partners. As a result, institutional patient engagement tends to primarily involve individuals possessing the necessary resources, connections and familiarity with the health system. This was reflected in a recent Canadian survey which found that most patient partners are women, white, university-educated, older and born in Canada (5). This underscores the lack of diversity among patient partners and demonstrates how *social inequities* shaped by access to material, social and cultural resources leads to stratification among patient partners based on their degree of privilege and can contribute to *social structural inequities* (7,8,11).

Populations experiencing the most health inequities are embedded in a structural web of exclusion from policymaking and research practices. These exclusions must be redressed if we are to improve the health of all people. In the context of patient engagement, fair and just health outcomes can be achieved if structurally marginalized patient partners have the *power* to be involved in decision-making and the *influence* to steer outcomes towards a goal of improving health equity. Despite the growing number of studies and frameworks on co-production in healthcare policy and research (12–14) there is a dearth of literature on power relations in patient engagement and few actionable tools to support praxis (reflection + action) – particularly as it relates to partnering with diverse individuals and equitable involvement in decision-making. To fill this knowledge gap, we draw on theoretical concepts of power, our own experience co-designing a novel model of patient engagement that is equity-promoting, Equity Mobilizing Partnerships in Community (EMPaCT) (https://www.womensresearch.ca/empact/), and extensive experience as patient partners engaged across the healthcare ecosystem. We introduce readers to a new conceptual tool that can be used to unpack, understand and report on issues of power as they relate to patient engagement and equity. In doing so, we build on Gaventa's conceptualisation of the power cube to create a *Power Wheel* that can be used to analyse the interspersion of power in the places and spaces of patient engagement. Our aim is to leave readers with a tool to help illuminate opportunities for equitable transformation and social inclusion so that health services can better meet the needs and priorities of all people. A glossary of terms used in the paper are listed in Table 1.

Term	Definition
Centering the margins	Centering decision-making around the needs of the most structurally marginalized (15).
Community table model of patient engagement	An independent table of patient partners united by a shared purpose, value or identity. The model emphasizes inclusivity, equity and shared decision-making by creating a safe and accessible space for diverse people and communities.
Diverse	The representation and inclusion of various gender identities, ethnicities, sexual orientations, abilities, and other intersectional identities.
Health system partner	People in the healthcare system who engage with patient partners for clinical practice, research or policy.
Influence	Social power where a social relation between two or more individuals determines an outcome such as a decision.
Institutional patient engagement model	The engagement of patient partners in healthcare institutions where patient partner perspectives can influence decision-making and project outcomes, encompassing research and institutional policy and/or clinical practice.
Patient	Describes a person with experience of a healthcare issue – including caregivers, families and friends (1).
Patient partner	A term used to describe a variety of decision-making roles held by patients that encompass clinical practice, policy and research.
Power	The ability (agency) of an individual (an agent) to act. Power is mediated through social relations and legitimized through social processes such as language, policies and the production of knowledge (15-19).
Power over	The asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other (16–18).
Power to	The ability of an agent to create an outcome (16–18).

Power Wheel	A conceptual tool that can be used to analyse the interspersion of power in places and spaces of patient engagement.
Power with	The ability of a group to act and mobilise together towards a collective outcome (16–18).
Quintuple aim	The Institute of Healthcare Improvement's framework for improving patient experience, population health, work-life of healthcare providers, reducing costs, and promoting equity.
Social inequities	Describes the unequal distribution of power, privilege and prestige across a society. Individuals who occupy positions of social advantage by virtue of their personal wealth and credentials are more able to access resources and services thereby creating further differentiation between social groups (11).
Social structural inequities	Refers to the hierarchical ordering of people based on their position in society that is determined by their level of power, prestige and privilege. When social inequality becomes systematically entrenched in a society such that it is institutionalized into policies and procedures that continue to differentiate between social groups, it is called social structural inequality or social stratification (11).
Structurally marginalized	Individuals or groups who experiencing systemic disadvantages and exclusion due to entrenched societal structures, policies, and practices. These structures often perpetuate inequality and limit access to resources, opportunities, and rights based on characteristics such as race, gender, sexuality, class, or disability.

Table 1. Glossary of terms

Concepts of power as they relate to patient engagement and equity

Power can be understood as the ability (agency) of an individual (agent) to act. In the literature on power relations, the ability of an agent to create an outcome is described as *power to*; and the concept of *power over* refers to the asymmetric relationship between two or more agents in a group such that one can influence the outcome over the other. In contrast, *power with* is the ability of a group to act and mobilise together towards a collective outcome (16–18). Power is mediated through social relations and legitimised through social practices such as language, policies and the production of knowledge (19,20).

In the context of patient engagement, power relates to the ability (agency) of patient partners (agents) to influence the outcome of decision-makers (actors) in the healthcare ecosystem. In patient engagement, power differentials are commonplace, as patient partners are often not involved in priority setting or direct decision-making. This leads to tokenistic patient engagement practices, where patient partner perspectives are not listened to or included in decision-making (21–23). In the context of diverse patient engagement, power influences who can participate in decision-making and the degree to which decisions are inclusive of diverse perspectives towards a goal of improving health equity. We define 'power to' in patient engagement as the ability of patient partners to engage in health system decision-making. When applying an equity lens, 'power to' means the ability of people who experience marginalizing social conditions to be included as patient partners in decisions. 'Power over' is the ability or degree to which patient partners can influence decision-making to improve health outcomes; and through an equity lens is the degree to which diverse patient partners can impact decisions that will advance their health. Finally, we define 'power with' as the ability of patient partners to group together for a collective goal of improving health outcomes; and through an equity lens is the ability of diverse patient partners to independently mobilise and influence health system decision-making.

It is important to note that populations who experience structural marginalization are less likely to have the material, social and cultural resources to be involved and influential as patient partners. Consequently, the range of patient engagement opportunities differs significantly between social groups, such that those who are more privileged wield more decision-making power and influence than those who are not – resulting in policies and services that are centered around the needs of those who already have better health. An alternative scenario to this, is to centre decision-making around the needs of the most structurally marginalized, in a concept known as *centering the margins* (15). From this point of view, policies and services that meet the needs of those experiencing the most health inequities are the most inclusive, and thus, will improve health outcomes for all people regardless of their degree of privilege. To centre the margins, power must be shared with structurally marginalized communities and processes of accountability must be created so that lived experiences directly influence equity-oriented decision-making.

Learning from an innovation in equity-promoting patient engagement: EMPaCT

Equity Mobilizing Partnerships in Community (EMPaCT) (https://www.womensresearch.ca/empact/) is an example of a scalable model of diverse and inclusive patient engagement co-created in direct response to exclusionary patient engagement practices. EMPaCT was co-designed by developing five key principles for building inclusive and diverse patient partnerships (8) (Table 2) and collectively imagining what a new model of patient engagement would look like if all these principles were applied in practice. In doing so, members of EMPaCT co-designed how, why and when they wanted to be engaged in projects by co-designing processes that are (7,8):

1. *Equity-oriented*: engaging with those least likely to be included with the greatest amount of outreach;
2. *Trauma-informed*: nurturing relationships of trust that recognise structures and systems of oppression and power imbalance; and
3. *Sustainable*: engagement spaces that are relationship-based and not bound to the lifecycle or funding of a specific project.

To increase their capacity to influence decision-makers, EMPaCT co-developed a process to translate the collective lived experiences of members into a written Health Equity Analysis (HEA) (paper forthcoming). Decision-makers (such as policymakers, researchers and clinicians) who seek a HEA request a seat at the EMPaCT community table, flipping power dynamics such that patient partners decide who they will engage with, the time and place of engagement, appropriate compensation for their expertise, and accountability structures for decision-makers who engage with them. Individuals on the table have a safe relationship-based space within which to share insights and influence recommendations, accruing power in ways not usually possible within other engagement models.

Five key principles for equity-promoting patient engagement
1. **Use an equity-oriented approach**
2. **Co-build sustainable safe spaces**
3. **Address issues of accessibility**
4. **Build capacity one relationship at a time**
5. **Do no harm**

Table 2: Five key principles for building inclusive and diverse patient partnerships (adapted with permission from Ambreen Sayani).

Reflecting a *community table model of patient engagement*, EMPaCT is a co-governed model of patient engagement that exemplifies how power can be shared between health system partners and patient partners towards a goal of improving health equity (7). As a group, we have increasingly discussed how power is shared both within our group, and with health system partners who engage with the table. We have reflected on how these power dynamics contrast with other models, such as the institutional model of patient engagement. We collectively identify asymmetric power relations as a key barrier to equity-oriented patient engagement. Inspired by Gaventa's conceptualisation of the power cube, we have developed a *Power Wheel* tool to help others better understand how power relations operate in the spaces and places of patient engagement so that they can be transformed and aligned towards a goal of improving health equity.

The Power Wheel

The Power Wheel (www.womensresearch.ca/powerwheel) is a conceptual tool that can be used to interrogate power relations in patient engagement. As a tool it can promote learning, reflection and transformative action so that places and spaces of patient engagement can become more inclusive of, and accessible to, diverse patient partners with a goal of improving health equity. The Power Wheel is an adaptation of the power cube, a concept first published in 2005 by John Gaventa as he reflected on citizen engagement and governance in the field of international development (24). Gaventa was concerned with the spaces of engagement, the places and levels at which citizen engagement was occurring and the interspersion of power within these dimensions (24). When considered together, these elements take the shape of a Power Cube – a framework which facilitates analysis of the dimensions of space, level and forms of power, and the interrelationship between each. While the power cube has been used to conduct power analyses in a variety of different settings (25), to our understanding, we are the first to adapt it to the field of patient engagement as a Power Wheel.

The Power Wheel (Figure 1) consists of three dimensions (place, space and influence) and each dimension has different levels through which power can be understood, configured and reconfigured through ongoing reflection and analysis. *Place* is a socially constructed area that has acquired meaning through human activities and interactions. Places hold different degrees of social, political and economic power depending on their level: micro, meso or macro. Patient engagement activities frequently occur at an individual-project, or micro-level – where patient partner perspectives are sought for specific clinical practice, research or localised policy projects. Meso-level places have intermediate-level impact, and meso-level patient engagement can lead to changes in institutions, organisations, or specific communities. Large-scale, wide-ranging impacts through social, political and economic changes are possible through macro-level places. *Space* refers to an abstract or physical setting where social interactions and relationships occur. Social and cultural forces determine the dimensions of space and can take three forms: closed, where decision-making occurs without patient engagement; invited, where patient partners are invited into healthcare spaces to contribute their perspectives on a predetermined topic or area of study; and created, informal or formal places where patient partners come together around a common need, and create their own boundaries around priorities, policies and programs. Finally, *influence* is social power where a social relation between two or more individuals determines an outcome such as a decision. Influence can take four forms in patient engagement activities: inform, where patient partners are merely provided with information about what is being done and what it means for them, and do not influence outcomes directly; consult, where patient partners are involved in providing feedback and input on a specific project; collaborate where their input is taken into account when decisions are made; and decide, where patient partners prioritise and decide what is relevant and important, and decisions are made by patient partners and implemented by institutions and projects.

In summary, place determines which level of decision-making is open for discussion; space determines the social relationships between people that shape conversations around decision-making; and finally, influence is the degree to which decision-making is shared towards a common goal.

The Power Wheel can be used to analyse the interspersion of power in places and spaces of patient engagement. For example, in Figure 2, power is distributed at a micro-level, invited-space that is open for consultation-level influence. The wheel in Figure 2 can exemplify a variety of institutional patient engagement activities that have localized impact – such as a quality improvement project in a specific department.

In Figure 3, power is distributed more broadly – with macro-level, collaborative decision-making, in a created space that was decided by patient partners. The wheel in Figure 3 is an example of a project where EMPaCT was engaged in national-level policymaking. As a community-table, EMPaCT is unique because members of EMPaCT decide which projects they want to engage with – and ultimately the engagement determines the degree of influence EMPaCT has on the outcomes of the project. Thus, EMPaCT always exerts multiple levels of influence, both determined by its novel model of patient engagement and the level of decision-making power available through a health system partner's project.

We are conducting a case study of power relations in different models of patient engagement using the Power Wheel. This work is forthcoming.

Using the Power Wheel to transform places and spaces of patient engagement

The Power Wheel is an action-oriented tool that supports better praxis in equity-promoting patient engagement. Researchers, clinicians and decision-makers in health systems can use the Power Wheel as a *reporting tool* to share their patient engagement practices**,** as a *reflective tool* to analyse the various dimensions of power within their patient engagement practices and as a *transformative tool* to identify tangible actions to modify spaces and places of patient engagement so they become more equitable in alignment with the goals of the Quintuple Aim.

We recommend using the Power Wheel to *report*, *reflect*, and *resolve* power asymmetries within patient engagement practices in the following ways:

1. *Report*: The current status of decision-making influence within a given patient engagement project can be reported as a figure in the methods section of presentations, reports and publications to promote transparency and accountability in patient engagement practices. We have given examples of how The Power Wheel (www.womensresearch.ca/powerwheel) can be used for reporting in Figures 2 and 3, and recommend that this becomes a component of regular reporting for all projects that include patient partners.
2. *Reflect*: The spaces and places of patient engagement within a given project can be analysed to question which perspectives are privileged in decision-making and which are absent. The diversity jigsaw (www.womensresearch.ca/wp-content/uploads/2023/05/EMPaCTDiversityJigsawActivity.pdf) is an activity that can be completed individually or as a group alongside the Power Wheel to unpack which identities, such as race, gender, class, sexual orientation, disability, etc. are currently included/ excluded and how issues of power asymmetry may be contributing to participation.
3. *Resolve*: The opportunities to transform power asymmetries can be identified and existing skills, knowledge, relationships and resources mobilized to promote health equity. This can be done using a strengths-based, relationship-driven approach to addressing challenges, fostering collaboration, and promoting inclusivity known as asset mapping (www.womensresearch.ca/wp-content/uploads/2023/05/EMPaCTAssetMappingActivity.pdf).

Conclusion

We believe that the practice of equity-oriented patient engagement is a pursuit of social justice. It is only by accruing power back to individuals from structurally marginalized communities that we can begin to advance equity. While patient engagement activities often have little to no influence on the determinants of oppression and exclusion, meaningfully including diverse patient partners in decision making is a key step towards improving health equity through the health system. When used as a tool for reporting, ongoing reflection and dynamic action, the Power Wheel enables us to rethink and redesign spaces and places of patient engagement to promote equity. We invite researchers, clinicians, and decision-makers to commit to addressing power inequities in spaces and places of patient engagement so that everyone can be involved in crafting priorities and influencing decisions that will lead to the betterment of our collective lives.

Contributors

Ambreen Sayani, Emily Cordeaux, Omar Khan and Alies Maybee contributed to the manuscript conception and design. The first draft of the manuscript was written by Ambreen Sayani. Emily Cordeaux, Kelly Wu, Fatah Awil, Victoria Garcia, Ryan Hinds, Tara Jeji, Omar Khan, Bee Lee, Alies Maybee, Desiree Mensah, Linda Monteith, Mursal Musawi, Marlene Rathbone, Jill Robinson, Ambreen Sayani, Staceyan Sterling, Dean Wardak, Isra Amsdr, Mohadessa Khawari, Salve Niwe, Azmina Hussain, Victoria Forster commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Competing interests

AS is a recipient of the Transition to Leadership Stream Career Development Award in Patient-Oriented Research from the Canadian Institutes for Health Research and is a Health Equity Expert Advisor to the Canadian Partnership Against Cancer (CPAC). All other authors declare no competing interests.

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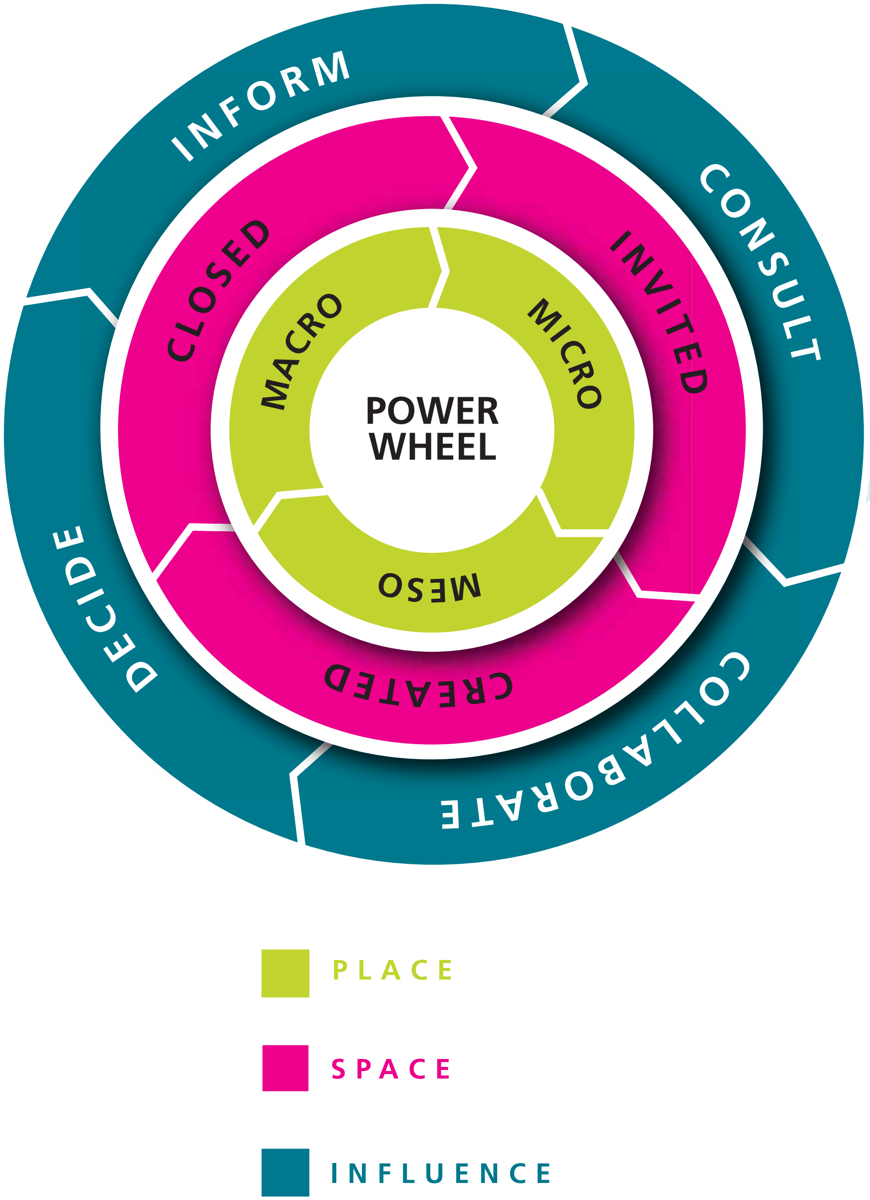
FIGURE TITLES

Figure 1. The Power Wheel

Figure 2. The Power Wheel: Institutional patient engagement for a localised quality improvement project

Figure 3. The Power Wheel: EMPaCT engagement for a national-level policy

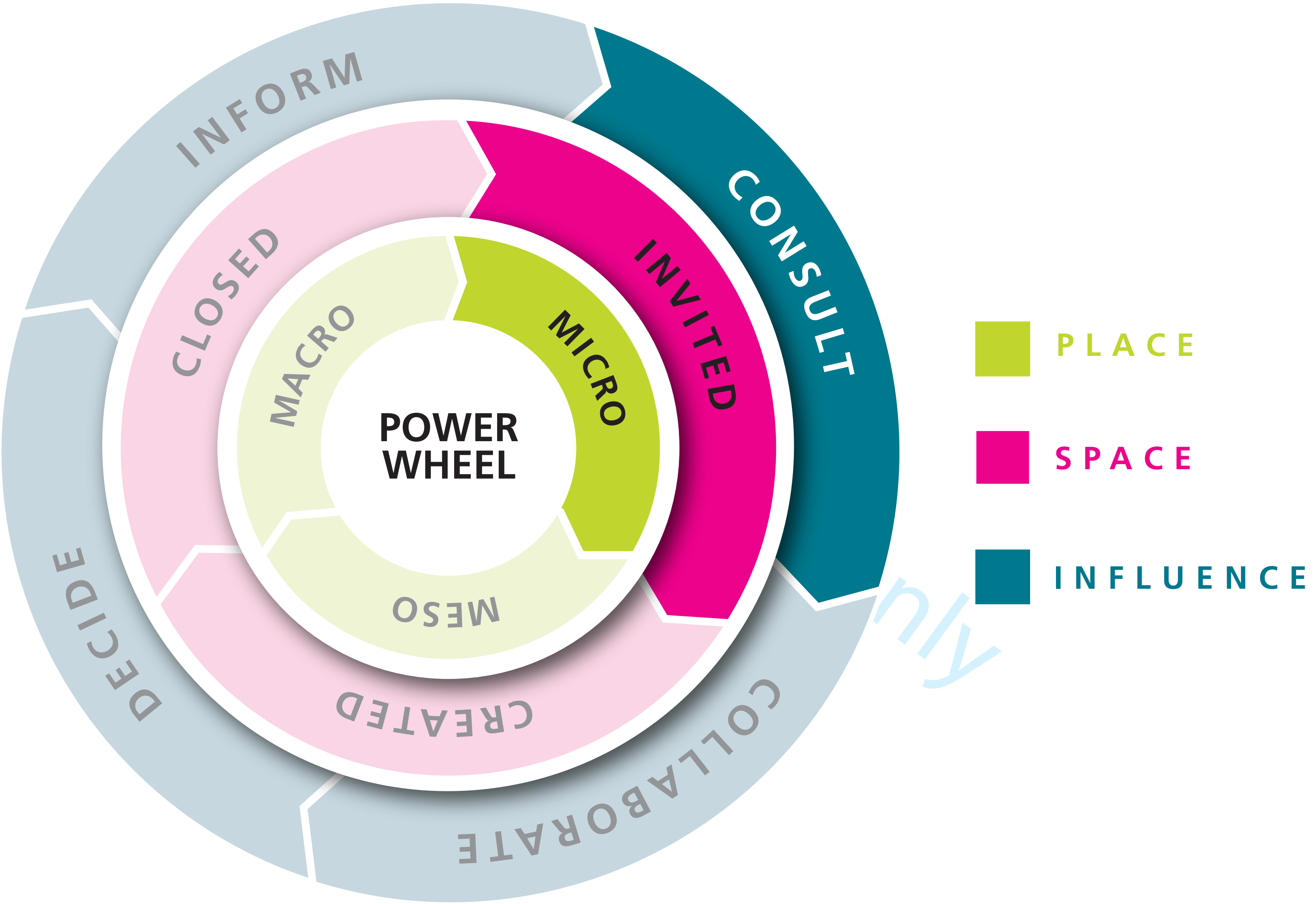
The Power Wheel



DIMENSION	LEVEL
PLACE: A socially constructed area that has acquired meaning through human activities and interactions and where social, political and economic power is held. Place directs the levels on which agents can exert influence and each level is interrelated to the others.	**MICRO:** Individual projects (clinical practice, research) or localised policy issues.
	MESO: Intermediate-level projects that lead to changes in institutions, organizations, or specific communities.
	MACRO: Large-scale social, economic or political issues that have a wide-ranging impact on society as a whole.
SPACE: An abstract or physical setting where social interactions and relationships occur between agents and actors. Space is typically confined within the ideological possibilities of the actors who create the space.	**CLOSED:** Healthcare spaces where decision-making occurs without patient engagement.
	INVITED: Healthcare spaces where patient partner perspectives on a predetermined topic or area of study are solicited.
	CREATED: Informal or formal spaces where patient partners collect and gather around a common need, creating their own boundaries around priorities, policies and programs.
INFLUENCE: Also understood as social power, in which a social relation between two individuals is able to impact an outcome such as a decision.	**INFORM:** Patient partners are provided information about what is being done and what it means for them. Patient partners have no influence on the outcome.
	CONSULT: Patient partners are involved in providing feedback and input on a specific project. Patient partner input is taken into consideration when decisions are made.
	COLLABORATE: Patient partners work together with decision-makers to develop alternatives. Decisions are made together with patient partners.
	DECIDE: Patient partners prioritise and decide what is relevant and important. Decisions are made by patient partners and implemented by institutions and project teams.

Institutional Patient Engagement

Quality improvement



Equity Mobilizing Partnerships in Community (EMPaCT)

Policy