Meaningful Involvement in Services in Health and Social Care – (MISHSoC)

Towards an Inclusive and Effective Public and Patient Engagement Strategy for Lived Experience Populations Facing Inequality

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Executive Summary

Introduction and Background to this Report

There has been increased efforts to engage those with lived experience in the design, implementation and monitoring of health and social care services, both in Ireland and internationally - whether these efforts are referred to as public and patient engagement, involvement or service-user involvement. There is, however, a central challenge in ensuring that service involvement includes individuals and groups who traditionally encounter significant barriers and inequalities in accessing care and whose views are least likely to be heard within services. In Ireland, these groups can comprise of five populations: those who use drugs and alcohol; those who experience homelessness; those who experience mental health challenges; those from migrant, minority ethnic and Roma backgrounds; and members of the Traveller community. Without understanding the meaning and challenges related to service involvement for such populations, involvement strategies are always likely to be ineffective for these excluded communities. There has not been a comprehensive effort to examine service involvement for the five groups in Ireland. There are, as a result, gaps in knowledge regarding: the state of current service involvement activities for such populations; and the goals and outcomes it should deliver within our health and social care system, and within the lives of individuals and their families. Crucially, there is also a lack of knowledge regarding the factors that limit or enable inclusive engagement for groups encountering exclusion.

In response to HSE efforts to advance public and patient engagement within the general health and social care system, the HSE National Social Inclusion Office, the HSE Mental Health Engagement and Recovery Office and Genio Trust collaborated to fund a research study to examine service involvement for some of the populations supported by these Offices who can encounter barriers to social inclusion. These populations include: (1) those who use drugs and alcohol; (2) those who experience homelessness; (3) those who experience mental health challenges; (4) those from migrant, minority ethnic and Roma backgrounds; and (5) members of the Traveller community. The purpose of this work was to inform the strategies of the two HSE Offices in relation to these groups, to support Genio Trust's service reform programmes in this area, and more broadly to inform any future HSE agendas with respect to public and patient engagement.

Researchers from the Irish Centre for Social Gerontology, at the Institute for Lifecourse and Society in the University of Galway, were commissioned to develop and conduct this research. The research study lasted for 24 months in duration, running from November 2021 to October 2023. This report documents the findings of this research study.

Aims, Objectives and Scope of this Research Study

The aim of this research study was to investigate service involvement in health and social care services for population groups susceptible to health, and care service inequalities, identifying current levels of engagement activities, existing understandings and goals, and the key challenges impacting involvement for these groups.

The research had five objectives. As agreed by the funders and the research team, these were:

1. To review international state-of-the-art knowledge on service involvement in care services for lived experience groups, and to assess the strategic view of involvement amongst national Irish stakeholders in relation to the design and delivery of services;

2. To examine on-the-ground experiences and perspectives of service providers and people who use services with respect to the challenges and opportunities of service involvement strategies for the five populations;
3. To explore in-depth the meanings, expectations and preferences associated with service involvement for members of these groups, and assess how their lived experience of health and engagement have shaped these perspectives;
4. To chart current service involvement activities and strategies within health and social care service delivery organisations working with the five groups;
5. To co-produce, with these groups, national stakeholders and service providers, a set of recommendations for service involvement to assist in informing HSE strategies and activities with these populations in the future.

The scope of the research study was focused on capturing the views of national policy and practice stakeholders, organisations and individuals who provide services, and people who use services. There is a particular prioritisation given to the lived experience perspectives of those within each population including eliciting their view on what needs to be done, or needs to change, to enhance the inclusivity and effectiveness of service involvement. While these perspectives will sometimes complement state-of-the-art 'expert' thinking regarding reform in complex health and social care systems, the research study was not designed as an implementation science or complexity science approach, nor was it an examination of all mechanisms to support change and reform in such systems. Such a focus sits outside the scope of this work.

For the purposes of this research, service involvement is understood as referring to instances where people who use health and social care services are involved in the design and development of those services, or related policies and practices, at individual, organisational or strategic levels. This research is focused on direct involvement of those who use services, rather than considering an expanded understanding of the term, which would include family members and carers.

Methodology

The study design incorporated three components. First, the research employed a mixed-method sequential design, incorporating a range of data-collection techniques and involving both quantitative and qualitative strategies. Second, the research was designed to account for perspectives from the multiple levels within a health and social care ecosystem that are implicated in policy and practice related to service involvement. Finally, in line with this multi-stakeholder aspect of the research, and to help embed the voices of those with lived experience within the research design, the research team drew on aspects of a participatory approach to guide the study. The research study comprised of six interconnected work packages (WPs), with each WP corresponding to one of the core study objectives.

WP 1: Existing knowledge and strategic context - Objective 1: The purpose of WP1 was to examine existing research knowledge on service involvement and the lived experienced groups, and to understand the strategic policy, practice, and advocacy context within which developments on this topic are being progressed. WP1 comprised of two research strands: a comprehensive literature review, and stakeholder interviews. Nine interviews took place with national-level social inclusion, and health and social care stakeholders with the goal of exploring the strategic view of involvement from policy, practice and civil society perspectives.

WP 2: Contextualising on-the-ground service-involvement – Objective 2: Twenty focus group discussions were conducted to explore on-the-ground, multi-stakeholder views of service use/delivery in general and service involvement as they pertain to the health and social care of the five population groups in the study. For each target population, one focus group discussion with service providers, and three focus group discussions with those who use services were completed. This meant five focus groups were conducted with service providers overall (39 people in total), and 15 focus groups were completed with those with lived experience across the five populations overall (101 people in total).

WP 3: Lived and life-course experience of engagement – Objective 3: Thirty-five individual life-course interviews were conducted to explore in depth the meaning of service involvement and the role of personal expectations in shaping views on engagement. In doing so, these interviews examined how interviewees' life-course experiences of health and social care, and their experiences as members of the different population groups informed their views. A secondary purpose of the interviews was to capture views of those who are less likely to participate in focus group discussions, and/or diverse groups who may require very specific sets of services.

WP 4: Service involvement service provider survey – Objective 4: An on-line survey was developed and distributed to service provider organisations working with or as a part of the HSE to deliver health, social care, and mental health services to each of the five population groups. The purpose of the survey was to provide an audit of the current activity level and the sort of strategies being used within organisations to involve members of the target groups in service involvement across Ireland. A final survey sample of 320 completed surveys were included in the analysis.

WP 5: Triangulation and translation – Objective 5: This WP comprised of two strands. The first strand sought to synthesise the individual sets of findings and to support the overall interpretation of the research across all WPs. The second strand involved the completion of two multi-stakeholder Consultative Forums, to agree priority areas and co-produce policy and practice messages. These priority areas and messages form the basis of the final set of recommendations presented in this study report (Chapter 8) and at the end of this summary.

WP 6: Peer researcher projects: In line with the aim of empowering voice to tackle health inequities, two members of each population group (10 people in all) were trained as peer researchers and conducted their own research projects in partnership with the research team. The final five case-studies are presented within the report. While they did not provide a specific basis for the conclusions of the report, they do provide additional insights regarding specific topics and challenges that are very much in line and complimentary to those conclusions.

Key findings and discussion points

The findings of this research are divided into three parts: current state of service involvement for the five populations; understandings of service involvement for the five populations; challenges for service involvement for the five populations.

Current state of service involvement – lots of activity, but not always of high quality

The findings of the research suggest that there is substantial service involvement activity happening, but that this activity is not always of high quality, varies significantly across the populations, and does not sufficiently engage members of the groups in daily practice.

For instance, 93 per cent of service provider survey respondents reported that their organisations conducted service involvement of some form. Just over two-thirds of respondents within this group (68%) noted that service involvement activities occurred on an on-going basis, while just under half of respondents (47%) reported that they engaged in involvement activities that comprised of sustained and continuous engagement with the same individuals. There were some differences in rates of activity across the groups, but these variations are minimal and must be interpreted with caution given the small number of survey respondents for certain populations. For some groups, such as those who use mental health services, and the Traveller community, there are long-standing examples of involvement and partnership approaches. For others, such as migrant, minority ethnic and Roma communities, and those experiencing homelessness, involvement is more embryonic although it is generally growing.

However, the research findings suggest that there are a number of limitations in existing involvement activities for these groups, despite the high levels of activity. First, it was found that there was generally a concentration on less intensive forms of involvement for many of the populations. Comment boxes or questionnaires were the most frequently reported means of involvement (51%), followed by focus group discussions (41%) and the inclusion of those with lived experience on committees and boards (37%). Second, study informants (national stakeholders; service providers; lived experience participants) indicated that were was still a tendency towards more superficial engagement, with service involvement activities more likely to take place at the levels of ‘engaging’ (individuals express views and influence some decisions), ‘consulting’ (individuals invited to provide views in surveys/meetings) or ‘informing’ (telling individuals about a service), rather than co-production and co-design levels. Third, study participants (particularly service providers, and national stakeholders) highlighted that service involvement for the groups could lack coordination, within and across organisations, and across the health and social care sector. Fourth, and in a related manner, there was a range of terminology and approaches in use in relation to service involvement, with no clear standardisation. Even in the case of mental health services, where there have been significant advances in involvement, there was clear frustration that a sufficient step change in the quality of services has not occurred.

Lived experience participants’ awareness of involvement approaches was found not to be extensive, with a lack of direct experiences of involvement activities amongst members of each population. This was particularly evident in relation to engagement beyond individual care planning, at the organisational, and at practice and policy levels. Many lived experience participants, across all groups, had rarely or never been asked for their views on the services they received. A lack of awareness and experience was more prominent for some groups (e.g. homelessness; migrant, minority ethnic and Roma communities) more than for others (drugs and alcohol; mental health), but these general patterns were evident for all groups.

Understandings of service involvement – consensus on goals and need for improvement

There was broad consensus on the meaning of service involvement amongst national stakeholders and service providers, who viewed it as something which operated in a multi-scalar way, across all aspects of service provision, and which includes a spectrum of varied activities. All participants in the research felt that involvement was about centralising the voice of those with lived experience in service design and delivery. There was also general agreement across the different sets of participants that service involvement was valuable and had the potential to affect positive change. Specific values which all research participants attributed to service involvement included compassion, respect, understanding, support, person-centredness, empowerment, involvement as a right, and inclusion.

Overall, the majority of participants considered the key goals of service involvement to be *better and more effective services*, and consequently *better health and inclusion outcomes*. People in this research, therefore, believed service involvement should lead directly to action and impact. Other goals of service involvement were also emphasised, but with some differences across informant groups. Many stakeholders, particularly those with policy and practice coordination remits, felt that service involvement should support long-standing health and social care policy agendas including those that seek to enhance transparency in services, and those that improve person-centred care. Service providers and those with lived experience described how service involvement should aim to: *capture the unique perspective of those with lived experience* (e.g. 58% of service provider survey respondents stated this); should *help those who use services to feel listened to and valued* (e.g. 49% of service provider survey respondents stated this); and should *empower* these groups. For participants with lived experience, the importance of representation, of being heard and of empowerment reflected their desire to address inclusivity, and their sense of not being valued, in the past. Some service provider participants highlighted that service involvement should also assist in culture change within the health and social care system, with 57 per cent stating that involvement activities should help to equalise power between service providers and those use services. Finally, some lived experience participants, particularly those from Traveller and migrant backgrounds noted that a goal of involvement should be to enhance cultural understanding and competence.

There was a collective desire for service involvement that is not just involvement, for involvement's sake. There was a strong view that follow-through and action must be key features of engagement processes. Taken together the research findings signal a call for a form of service involvement that drives change – certainly in terms of individual level outcomes but also in terms of the responsiveness and inclusiveness of the health and social care system, and the position of the five groups in relation to that system.

Significant challenges to overcome and harness

Five challenges were identified as impacting the effectiveness and inclusivity of service involvement for the five population groups: 1) leadership and commitment; 2) implementation and action; 3) population capacities; 4) trust; and 5) representation, stigma and discrimination. The challenges influence the efficacy and sustainability of involvement strategies for groups susceptible to unequal service access and prolonged social exclusion.

Leadership and commitment: Findings indicated that while positive examples and developments were evident, there were two areas of concern for study participants. First, with respect to national strategic direction and prioritisation, research findings showed that many individuals included in the study felt there was an absence of a high-level commitment to supporting service involvement for the five populations groups. Almost half of service provider survey respondents (47%) felt that service involvement for the population groups had not been given adequate attention within national government policy. In addition, almost a third (31%) of service providers did not agree that there was strategic high-level leadership and sufficient resources. Participants from lived experience groups felt that they were not always considered within the priorities set by senior management at the highest levels of health and social care. Second, in terms of organisational processes and commitment, there were more contrasting views across study informants. The majority of service provider survey respondents (78%) felt that there was strong leadership and a positive ethos of engagement within their own organisation, with 78 per cent also stating that the input of people with lived experience was valued by their organisation. That said, almost a quarter of respondents (23%) still felt that leadership in their own organisations was not sufficient. This proportion increased for those working with mental health service user (36%), and those from migrant, minority ethnic or Roma communities (41%). Qualitative findings were more likely to draw attention to these sorts of issues. Service provider focus group participants emphasised the challenges in ensuring organisational buy-in, with some of these participants and some of those with lived experience noting that current activities were, as a result ineffective in many cases, and often tokenistic. Where the culture and processes of a system, or an organisation within that system, fails to embrace involvement activities, then the development of a genuine ethos of engagement is unlikely to evolve or persist beyond time-bound projects.

Implementation and action: Factors and concerns related to implementation and action emerged as one of the dominant themes within the research. This not only included the simple lack of involvement implementation processes for the five groups, but also the absence of resources; deficiencies in measuring service involvement and accountability; and inadequate follow-through in enacting changes arising from engagement activities. All informant groups in this research highlighted the need for service involvement agendas and programmes to be supported by the provision of adequate resources. Over two thirds of all service provider survey respondents (69%) reported that there was a lack of resources within the health and social care sector to support service involvement in general. There were higher levels of agreement among those working with those with mental health challenges (77%) and those from migrants, minority ethnic and Roma communities (94%). It was asserted in the qualitative research strands that successful implementation must be driven by evidence of effectiveness of outcomes, including the use of key performance indicators. However, despite strong consensus among stakeholders and service providers on the need for comprehensive and effective measurement of service involvement activities, these participants indicated that measurement of service involvement was not widespread. Without measurement, participants felt that service involvement would not be truly prioritized as a sector wide agenda and as an organisational objective. The importance of follow-through action and generating impact arising from service involvement activities was also highlighted by study informants. However, it was this absence of action that served as one of the biggest challenges facing the longer-term implementation of service involvement. Participants highlighted that the lack of follow through means that those with lived experience can become disappointed and disillusioned when their feedback or contribution does not go anywhere.

Population capacities: It was generally recognized by all informants that the capacities of the five diverse populations needed specific consideration, and to be appropriately accounted for, harnessed and empowered within the development and roll-out of service involvement programmes. The findings of this research point to the need for a capacity building approach with respect to service involvement, that attends to fostering the potential of individuals and groups for engagement across three key dimensions. First, with respect to psychological readiness, lived experience participants argued that many people in the study's population groups may *not be in the right psychological space* to contribute in a meaningful way, or to participate at all in service involvement processes. This was recognised across all informant groups. For example in the service provider survey, 55 per cent of those who responded agreed that precarious living circumstances and social exclusion among those who use services could disrupt service involvement activities; those providing services to migrant and Traveller communities were much more likely to agree with 94 per cent and 88 per cent of respondents in these categories, respectively, agreeing. Second, in terms of confidence and self-esteem, several lived experience participants discussed how they or their peers may place little faith or value on their own opinions and views in relation to services. For some, this was related to not feeling 'qualified' to take part. Some lived experience participants described how they would feel especially nervous to engage with those who they perceived to be in positions of power relative to theirs, for example doctors or other professionals. Third, lack of knowledge and familiarity around service involvement and its key concepts, systems and processes can lead to some people from these groups being reluctant or technically under-prepared to take part in engagement activities.

Trust: There was good agreement across all study informant groups that trust was a key factor in service involvement with these populations. Concerns regarding distrust were expressed by those with lived experience, and stakeholders and service providers alike, and represented a prominent barrier to engagement for and with the groups. More than half of respondents to the service provider survey (53%) felt that members of these populations were less likely to have trust or confidence in service involvement processes. Factors that undermined trust emerged from different levels of the health and social care system and included structures and systems, and/or negative experiences of dealing with individuals in services, or previous experience of service involvement activities. Trust was also influenced by trauma-based fears around certain places, people and activities, and by perceived and actual threats to privacy and confidentiality. People with lived experience in particular spoke about their concerns for the potential consequences of sharing their honest views for future access to services. Together these factors could reinforce a perception amongst many lived experience participants that they were neither valued as users of services, nor that their views would be acted upon. It was generally noted that a more substantial investment in trust building and in fostering respect is required to respond to the negative experiences and interactions that some members of these groups may have had in health and social care services and in wider society.

Representation, stigma and discrimination: Challenges related to representation, stigma and discrimination emerged strongly within the research, with prevalence and implications highlighted by each set of study informants. People from all five groups in this study faced these challenges to varying degrees due to their status and experiences. Challenges regarding representation, related to how service involvement can under-represent individual identities and the diversity within populations, presenting a more homogenised profile and set of views of a particular group. Over half of the respondents in the service provider survey (51%) reported difficulties in recruiting an appropriately diverse and inclusive sample of the groups. Some members felt that the lack of adequate representation reflected a more long-standing and pointed neglect of the views of particular sub-groups. Challenges related to stigma could arise from negative associations, beliefs and stereotyping that were linked to the circumstances, status or prescribed group identities of the five groups. Ethnic based stereotyping was most prominent for members of the Traveller and Roma communities. However, other forms of stigmatisation – for example prejudice, ignorance, rejection, labelling and perceived loss of status – were an issue for those who use drugs and alcohol services, those experiencing homelessness, migrant individuals and those who use mental health services. Almost all groups were thought to have encountered discrimination. Within services, unfair treatment manifested in a lack of access to health or social care services and supports (for example due to migration status), or a poor level of services (for example poor quality accommodation or food because of homeless or drug use status). For those from racialised groups or ethnicities – individuals from Traveller, migrant, minority ethnic, and Roma communities – discrimination was most often encountered as racist behaviour and treatment.

Conclusions and Recommendations: Operationalising an Inclusive and Effective Strategy for Public and Patient Engagement

Based on the research findings, and representing the core conclusions of the study, seven key development areas can be identified for creating an inclusive and effective strategy for public and patient engagement for the five groups. The development areas, along with the recommendations, are rooted in the research evidence and based on the outline policy and practice priorities and messages coproduced by the Consultative Forums.

Development Areas

Balancing Top-Down Drive and Bottom-Up Direction: A balanced development of service involvement is required to embed public and patient engagement for the five groups within the health and social care system. This development must be coordinated by national policy and HSE Health Region implementation, but informed by on-the-ground needs. The research suggests that what progress has been made is not at a scale to generate significant change and is often disconnected. Coordinated strategic efforts are needed to address challenges in the groups' engagement. This should be evident in a clear commitment amongst national HSE and Department of Health leadership, Health Region management teams and professional groups, which recognises the value of involvement for these groups, and prioritises, governs and leads its development. Coordinated efforts must also take the form of a long-term national development programme for the five groups. Otherwise, engagement will be another additional demand on organisations already under strain. Nevertheless, strategic and Health Region level efforts must integrate on-the ground knowledge, and lived experience perspectives, as a part of the development process to enhance effectiveness and relevance of engagement. Health Regions and provider organisations must work to prioritise good quality engagement for the groups. Organisational decisions regarding appropriate allocation of staff and time will help nurture a wider culture of engagement and move the emphasis from sole service delivery.

Connecting the strategic, policy landscape: The range of different strategies and polices that are linked to involvement creates confusion around public and patient engagement for the five populations. This compounds the absence of a clear strategic direction. Just as those with lived experience spoke about difficulties in navigating the care system, service providers and national stakeholders were perplexed at the myriad of strategies and documents that have to be considered. There is a need to consolidate and simplify the objectives and guidance for public and patient engagement for the five groups. Otherwise, engagement activities will become further fragmented, demotivating collective action and local innovations.

Establishing sustained multi-level, multi-form implementation: Public and patient engagement must be expanded for the five groups to include activities at different levels of the care system, and different forms of engagement. Involvement is currently more likely to take place in support of individual-level service delivery. Engagement for these groups must be embedded to a greater extent within organisations (in terms of: service design and strategic direction) and within strategic-level decision-making structures like those within the HSE, its Health Regions and, where appropriate, the Department of Health. The findings also indicate the need for different types of engagement across these levels to accommodate different needs and different population sub-groups. A shift to co-production and partnership approaches is required. Nevertheless, under budget and time constraints, all methods may serve a purpose as a part of a flexible strategy. A pre-engagement consultation with a diverse sample of the targeted population should help inform initial choices.

Measuring effectiveness and action: The need for action arising from public and patient engagement was highlighted by all participants. This ranged from calls for implementable tasks and measurable impact, to a desire to see real change in services, to simply 'being listened to'. Although resourcing is critical, people with lived experience were clear that it was the commitment to 'follow-through' that was often key. Measurement, in terms of key performance indicators (KPIs), and accountability, in terms of governance and responsibility, must be present at all levels, if engagement is to be really taken seriously. In addition, there is a case for stronger integration between involvement structures across all levels, where actions arising from local engagement practices, should be championed and implemented by higher level actors, and vice versa. Otherwise, engagement for the five populations will remain shallow in its embeddedness and narrow in its capacity for change.

Embedding inclusive engagement: The inclusivity of public and patient engagement must be improved to enhance the appeal and effectiveness of involvement for the five populations. Flexible and accessible strategies are needed to improve the fit between approaches and a groups' preferences and life circumstances. Tailored supports, such as those that account for logistical, financial and psychosocial restrictions, inclusive communication and cultural inclusion will help address specific needs of groups and the structural barriers that they may face. These features reflect those that study participants found helpful to counter the challenges identified in this research. The lack of consideration of the intersectional positions of people with lived experience also represents a barrier to developing inclusive engagement. Overlapping population composition, and areas like mental health, housing, deprivation and recovery pathways, must be considered. Engagement agendas must be sensitive to these intersections when designing and implementing activities. Additionally, there is a need to go beyond a single service focus, to a more integrated engagement strategy that accounts for the all the services people use.

Building trust as a prerequisite and as an outcome: Public and patient engagement for these five populations is intrinsically linked to trust in engagement structures, and the health and social care system. Trust serves as a prerequisite for effective engagement, where issues of distrust reflect perceived breaches in fairness and transparency when using or trying to access care services. Building trust must, therefore, be viewed as a core component of the early stages of the engagement process. However, the link between trust and engagement is mutually reinforcing, where transparent engagement can play a core role in rebuilding trust in the care system for these populations. Reciprocal relationships – founded upon common goals of equitable communities and acceptance of mutual self-interests – are critical in trust relations between actors in complex systems. Meaningful and sustained engagement and action will help establish trusting relationships, but so too will transparency and clear lines of communication. Desired outcomes may not always be achievable, but a genuine honest process must be.

Driving an equalising, agency empowering agenda: Public and patient engagement must drive an equalizing approach for the five population groups. This is in terms of health and social care service access, opportunities to express voice, and well-being and inclusion outcomes. Engagement must therefore aim to address both the power imbalances that can develop within a traditional, professionally-driven health and social system, and that can arise from the gaps and deprivations in how such systems treat these groups. Being engaged in the design and delivery of care services should function to empower the agency of individuals and groups with respect to the quality of services they receive, and has the potential to engender a greater sense of social integration for these groups. In this regard, public and patient engagement may help provide a clearer path towards full membership of society. Investments in capacity building and the development of a life-course trauma-informed approach to engagement would enable agency. A resource allocation model that distributes a more appropriate share of resources to engagement for the five groups would be central to this.

Recommendations

This report presents 15 recommendations for advancing inclusive and effective approaches for public and patient engagement for the five populations in Ireland. The recommendations are rooted in the lived experience evidence and the conclusions presented in this report and, critically, are based on the outline policy and practice messages coproduced by the Consultative Forums. With reference to Figure 1, the recommendations cut across the seven areas of development, and can be broken into six broad categories: (1) Securing strategic prioritisation and direction; (2) Establishing critical resources and structures (3) Generating and sustaining positive change; (4) Setting values and principles (5) Enabling a culture of engagement (6) Empowering and flexible approaches. The recommendations are designed to nurture a multi-level system approach that should enhance integration and coordination across engagement activities for these groups, while also allowing for the need for discrete leadership, implementation and action at each level of the health and social care system. Practical actions are suggested for each recommendation to assist in their operationalisation.

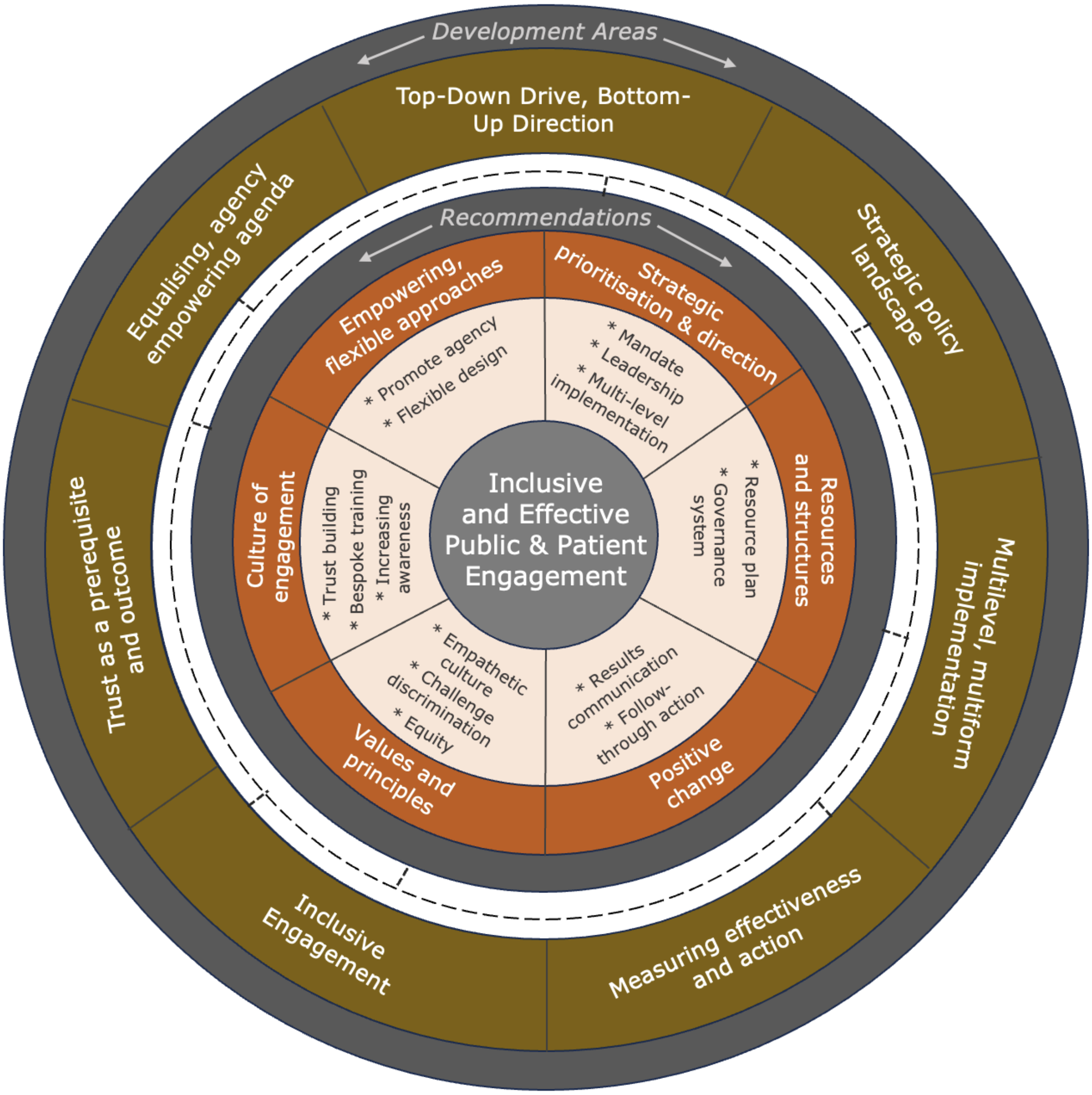

Figure 1: Inclusive and effective public and patient engagement for the five groups

Concluding Remarks

A key part of this study has been to isolate shared challenges across the five populations, and to point to common elements of a more inclusive and effective pathway to engagement in health and social care services. These challenges need to be recognised and addressed, and these elements need to be embraced. Otherwise, there is a danger that public and patient engagement will lose traction, will be perceived as meaningless, and will become more of a destructive than constructive force for individual and group agency. Reflecting the consensus view of the majority of informants in this study, national stakeholders, service providers and lived experience participants were clear about the potential of engagement, and were hopeful in terms of its future impact. Throughout this work there was a collective will to elevate the position of individuals and groups in diverse and marginalised populations as contributors to, and leaders of, their health and social care services. Public and patient engagement was in overall terms seen as a powerful means of realising that will, and of fostering a recognition of the agency of individuals and groups. It is critical that this collective will is appropriately supported for these groups. Otherwise, those most in need, will remain outside of the system. In doing so, there are likely to be ethical and social inclusion gains, but also gains in terms of system efficiency and system financing, where services are more likely to be effective and cycles of treatment and support more impactful.

1. Introduction

1.1 Justification and Gaps in Ireland

There have been increased efforts to engage those with lived experience in the design, implementation and monitoring of health and social care services, both in Ireland and internationally (Beresford, 2019; HSE, 2020). Whether referred to as Public and Patient Engagement, Public and Patient Involvement or service-user involvement, these service involvement strategies aim to embed the voices of target populations within practice and policy development, enhancing the potential for improved services and better health outcomes (McEvoy et al., 2019). Although encompassing a wide range of activities, there is in general, growing evidence of consultation, engagement and coproduction processes across individual, organisational and strategic levels of care systems (De Freitas, 2017; McMillan, 2019). In Ireland, the commitment to nurturing a culture of meaningful engagement in care services is demonstrated most recently by the Health Service Executive's publication of the 'Better Together: Health Services Patient Engagement Roadmap' (HSE, 2022b), and its investment in capacity building to support engagement, such as the establishment of the National Patient Forum (HSE, no date (a)) and the embedding of peer-support roles within HSE occupational grades (HSE, 2023).

There is a central challenge in ensuring that service involvement accounts for and supports the position and circumstances of those most in need. This includes individuals and groups who traditionally may experience significant barriers and inequalities in accessing care and whose views are least likely to be heard within services (Ní Shé et al., 2018; Snow, 2022). In Ireland, such populations may comprise of, albeit not exclusively, five groups: those who use drugs and alcohol; those who experience homelessness; those who experience mental health challenges; those from migrant, minority ethnic and Roma backgrounds; and members of the Traveller community. There is also considerable overlap in composition across these groups. Without understanding the meaning and challenges related to service involvement for such populations, involvement strategies are always likely to be ineffective for these communities (Ocloo and Matthews, 2016). Consequently, individual members are more likely to be left behind, leading to services that tangibly fail to support their needs, and symbolically reinforce the diminished voice of the groups. It is important to recognise that there have been some notable advances with respect to service involvement for the five populations, and other similar groups. In international research, this includes the increased number of studies, pilot projects, and frameworks that have emerged from research, practice and policy work (De Freitas, 2017; Andreassen, 2018). In national implementation it includes, for example, the establishment of the HSE Mental Health Engagement and Recovery Office to help ensure the voice of those who use services and their families inform service design, delivery and improvement. It includes the ongoing peer-led Primary Health Care for Travellers Project, and more generally, it includes the increase in peer support activities and peer-worker roles within care services (HSE, 2023).

However, there has not been a comprehensive effort to examine service involvement for the five groups in Ireland. Apart from isolated projects, the lived experience perspectives of these individuals, and the views of key national stakeholders and service providers charged with implementing engagement programmes, have not been captured with respect to how service involvement should be developed for such populations. Consequently, there are gaps in knowledge regarding: the state of current service involvement activities for such populations; the kind of activities it should entail; and the goals and outcomes it should deliver within our health and social care system and within the lives of individuals and their families. Crucially, there is also a lack of knowledge regarding the kind of factors that limit and enable inclusive engagement. As a result, there is an understandable concern that the specifics of these five populations and the past and present circumstances of their lives have not been properly understood or assessed from an involvement perspective.

1.1.1 Gaps in international knowledge

Internationally, gaps in knowledge remain with respect to how service involvement can account for the health and social circumstances and the profile characteristics of the five populations (Williams et al., 2020; Amann and Sleigh, 2021; Micsinszki et al., 2022).

First, there are concerns about the capacity of involvement approaches to reflect the significant diversity within each of these populations, and to cater for the differential experiences, needs and agencies of their individual members (Snow, 2022). For example, those who encounter different mental health challenges (e.g. first episode psychosis; severe and enduring mental illness), those who are in different drug culture communities and use different recovery pathways (e.g. club-culture drug use; community-based recovery), or those who have experienced different migration pathways (e.g. labour migration; undocumented migration) (Daya et al., 2020; Ocloo et al., 2021). Sub-groups may also differ based on demographic and intersectional characteristics that establish distinct circumstances and intersectional identities for individuals to negotiate. This includes those based on gender and sexual orientation (women in homelessness; Traveller members of the LGBTQI+ communities), and those of different ages (older opiate users; older homeless adults; children and adolescents using mental health services). But diversity is also linked to the spectrum and complexity of needs that people possess, and the range of services they require (De Freitas and Martin, 2015).

Second, the lives of some members of these populations can be characterised as precarious, being subject to greater risks of social exclusion, health service inequalities and poorer health outcomes (Andrews and Heerde, 2021). While different mechanisms can create these risks, a life-course accumulation of exclusion is often observable for each population. For some individual members, it is the uncertainty of their situations that can be problematic (for example migration status; housing status; treatment status), generating higher levels of stress, and creating practical barriers that constrain people's capacity for positive health behaviours and engagement (Røhnebæk and Bjerck, 2021). For others, environmental insecurity is likely to be a primary source of risk – including the complete absence of housing or insecure housing tenure for those in homelessness, sub-standard accommodation for members of the Traveller community, or displacement for some members from migrant backgrounds (Clifford et al., 2022). In addition, entrenched structural discrimination based on race and ethnicity and stigmatization have been documented for a number of these populations, with the former compounding service access challenges for the Traveller community and visible ethnic minorities, and the latter encountered to some degree by all groups (McFadden et al., 2018; Condon et al., 2019).

Third, a number of these populations can encounter issues around communication and a lack of familiarity with respect to health and social care systems. For some of the groups, these challenges may arise from an extended period of disconnection from services, and stem from a lack of confidence and health literacy in terms of articulating needs (Mc Fadden et al., 2018). For others, who may have arrived in Ireland from another country, such challenges arise directly from poor English language proficiency and a lack of knowledge regarding how to negotiate the care system (e.g. Dawson et al., 2017; Røhnebæk and Bjerck, 2021). These challenges can combine with any risks and disadvantage accrued to limit individual and collective capacity for engagement. Such challenges also combine with the hierarchical decision-making structures of complex health and social care systems to limit the opportunities given to members of these groups for service involvement (Rosenberg and Hillborg, 2016).

The characteristics and situations of the five populations demand specific consideration around designing service involvement for these groups. However, they also point to how service involvement can be potentially harnessed to account for these facets, leveraging capacity for representation and for countering long-standing disadvantages.

1.2 Background to this Report

In response to HSE efforts to advance Public and Patient Engagement within the general health and social care system, the HSE National Social Inclusion Office, the HSE Mental Health Engagement and Recovery Office and Genio Trust collaborated to fund a research study to examine service involvement for some of the populations supported by these Offices who can encounter barriers to social inclusion. These populations include: (1) those who use drugs and alcohol; (2) those who experience homelessness; (3) those who experience mental health challenges; (4) those from migrant, minority ethnic and Roma backgrounds; and (5) members of the Traveller community. The purpose of this work was to inform the strategies and activities of the two HSE Offices in relation to the groups, Genio Trust's service reform programmes in this area, and more broadly any forthcoming HSE agendas with respect to public and patient engagement. Researchers from the Irish Centre for Social Gerontology, at the Institute for Lifecourse and Society in the University of Galway, were commissioned to develop and conduct this research. The research study lasted for 24 months in duration, running from November 2021 to October 2023. This report documents the findings of this research study.

It was recognised from the outset of this work that service involvement with those who use mental health services has a longer history of development in Ireland (see for example: A Vision for Change – Department of Health and Children, 2006), than with the other populations in the study. Including the various groups together in this research was not for the purposes of comparison, or cross-sector performance appraisal. Instead, the goal was to examine shared meanings, challenges and opportunities while identifying possible population and sector specific learnings that may hold relevance to all groups in the research.

1.3 Aim and Objectives

The aim of this research study was to investigate service involvement in health and social care services for population groups susceptible to health, and care service, inequalities, identifying current levels of engagement, existing understandings and goals, and the key challenges impacting involvement for these groups.

The research had five objectives. As agreed by the funders and the research team, these are:

1. To review international state-of-the-art knowledge on service involvement in care services for lived experience groups, and to assess the strategic view of involvement amongst national Irish stakeholders in relation to the design and delivery of services;

2. To examine on-the-ground experiences and perspectives of service providers and people who use services with respect to the challenges and opportunities of service involvement strategies for the five populations;

3. To explore in-depth the meanings, expectations and preferences associated with service involvement for members of these groups, and assess how their lived experience of health and engagement have shaped these perspectives;

4. To chart current service involvement activities and strategies within health and social care service delivery organisations working with the five groups;

5. To co-produce, with these groups, national stakeholders and service providers, a set of recommendations for service involvement to assist in informing forthcoming HSE strategies and activities with these populations.

In addition to the core research team, it was agreed that the research should be supported by two governance committees to provide oversight and guidance regarding the research study. A Steering Committee comprised of collaborators and representatives from each of the funding organisations, and included individuals who worked in support of each of the populations and the service provider organisations who provide their services. Meeting at regular intervals, the Committee helped shape the focus of the work and helped facilitate the field work, through connecting the research team to key stakeholders and organisations. The members of the Steering Committee are listed in Appendix 1A. A Project Advisory Board was established as an interdisciplinary and lived experience advisory panel. Its membership comprised of individuals external to the research team. This included Steering Committee members along with three academic research experts from the fields of public health, clinical and inclusion health and social work and policy, and five people with lived experience from each of the groups, who worked in peer support roles. It was not feasible and not intended for the Project Advisory Board to be representative of all organisations working with these populations. The Project Advisory Board met during the study, at six-month intervals approximately. The terms of reference of the Board and the list of its members are presented in Appendix 1B.

The data collection for this research was conducted from March 2022 to June 2023, with the final report submitted to the funders in November 2023. While the study was completed when the HSE was organised into Community Health Organisations (CHOs), the report will reference the newly created *Health Regions* (HRs) as appropriate.

1.4 Defining the Scope of this Research Study

The scope of this research study was focused on capturing the views of national policy and practice stakeholders, organisations and individuals who provide services, and people who use services. There is a particular prioritisation given to the lived experience perspectives of those within each population and what in their view needs to be done, or needs to change, to enhance the inclusivity and effectiveness of service involvement. While these perspectives will sometimes complement state-of-the-art ‘expert’ thinking regarding reform in complex health and social care systems, the research study was not designed as an implementation science or complexity science approach, nor was it an examination of all mechanisms to support change and reform in such systems. Such a focus sits outside the scope of this work.

This report uses the term service involvement to describe activities and strategies related to engaging those who use health and social care services. While recent and formal developments in the health and social care system in Ireland refer to Public and Patient Engagement, this is just one of many terms in a wider field of activity and study. In research, and in many practice environments (including those within Ireland), definitions and meanings of involvement and the language describing these strategies can vary considerably. ‘Service-user involvement' is generally the overarching dominant terminology in academic literature (Millar et al., 2016; Greenhalgh et al., 2019), but the term 'user' is generally critiqued as ignoring the personhood of individuals and their multifaceted identities beyond that based on service use. *Service involvement* is therefore employed as an overarching umbrella term, that incorporates a spectrum (or ladder) of activities that vary in terms of where power and control between service providers and those who use services lie in the decision-making process. This spectrum ranges from information and consulting activities at one end where the parameters are firmly set by service providers/professionals, through engagement activities where views and opinions of those who use services are sought about service provider-directed service changes, to co-design and co-production activities which involve shared and reciprocal decision-making (Tierney et al., 2016; McMillan, 2019). In this study, the term service involvement also includes peer-led activities, and community partnership strategies (joint goal setting and shared working approaches).

For the purposes of this research, *service involvement* is understood as referring to instances where people who use health and social care services are involved in the design and development of those services, or related policies and practices, at individual, organisational or strategic levels. This research is focused on direct involvement of those who use services, rather than considering an expanded understanding of the term, which would include family members and carers. A full discussion of the evolution of service involvement and its various terminologies and approaches will be detailed in Chapter 3 and Appendix 2A.

1.5 Structure of the report

The structure of this report is as follows. In the remainder of Chapter 1, a brief overview of the five populations in Ireland is presented, followed by an overview of recent Irish developments in policy and practice related to public and patient engagement. Chapter 2 presents an overview of the study methodology, including a description of the mixed-method study design and the core data collection work packages (which correspond to each of the study objectives), and an overview of the research participants and ethical considerations. Chapter 3 presents the findings of a comprehensive review of the international literature on service involvement, describing first developments in the general field and then reviewing state-of-the-art research with respect to frameworks, approaches and research findings on barriers and enablers for each of the populations. Chapters 4 - 6 present the empirical findings of the research. Chapter 4 describes the state and status of service involvement for the five population groups in Ireland, and presents levels of activity and insights into the nature and quality of that activity. Chapter 5 describes research findings on understandings of service involvement, and details different perspectives on the meanings and goals of engagement activities with these groups. Chapter 6 presents findings on the key challenges impacting service involvement for the five populations in Ireland, and outlines overarching themes relevant to all of the populations as well as differences and similarities across the groups. Chapter 7 presents a discussion of the research findings, drawing together the core findings and unpacking their significance in relation to the international research literature and the specifics of the Irish context. Finally, Chapter 8 presents the conclusions and recommendations of the research. In doing so it delineates the key areas of development for operationalising an inclusive and effective public and patient engagement strategy for the five populations, and presents 15 recommendations for policy and practice to support this operationalisation.

1.6 Overview of the Five Population Groups in Ireland

A brief overview of the five groups is now presented. It should be noted that available information on these populations varies considerably, meaning descriptions will also vary.

1.6.1 People who use drugs and alcohol

The 2019-2020 Irish National Drug and Alcohol Survey found that the prevalence of Alcohol Use Disorder was 15 per cent in the general adult population, and that 7 per cent of the population reported illegal drug use within the previous year (Mongan et al, 2021, 2021). In 2022, there were 12,099 treatment episodes in the National Drug Treatment Reporting System (NDTRS), which records and reports on cases of drug and alcohol treatment in Ireland. This represented the highest annual number of people recorded by the NDTRS to date, with 34 per cent of people reporting cocaine as the main drug being used, 33 per cent reported heroine or other opioids, 19 per cent reported cannabis and 11 per cent reported benzodiazepines. The group comprised of 28 per cent females and 72 per cent males, with a mean age of 33 years. Twenty-two percent of the population group were unemployed and 14 per cent experienced homelessness. In overall terms, while there are certain socioeconomic factors associated with prevalence of drug use (such as age (15-34 years), neighbourhood deprivation and unemployment) there remains significant diversity in terms of educational background and the range of age groups reporting drug use. There are also notable differences in cohort groups, as per the type and frequency and nature of drug use and the sort of supports that are sought. For example, people who report the use of cocaine are more likely to be in the 19–34 year-old age group, while those reporting the use of opioids are more likely to be aged 35 years and over and steadily increasing up to 50 years and over. Different sets of needs are also associated with different sub-groups, such as those who use club drugs (including in chemsex or Party and Play activity), those who are older and use opioid drugs, and those in recovery. As illustrated by 2022 statistics on national drug treatment demand, drugs treatment services can be categorised into: Tier 1: GP services (3%); Tier 2: low intensity specialised community-based services (10%); Tier 3: high intensity specialised community-based services (69%); and Tier 4: high intensity specialised in-patient services (12%) as well as ancillary supports, e.g. treatments sites within prisons (6%).

1.6.2 People experiencing homelessness

As of September 2023, there were 12,827 people experiencing homelessness in Ireland. This number is made up of 8923 adults (70%), and 3904 children (30%). This represents a 17 per cent increase in numbers of people experiencing homelessness from the previous year. These statistics include those availing of state emergency homeless accommodation. They do not include those who are in ‘own-door’ temporary accommodation, those staying in domestic violence refuges, people who are living in the Direct Provision system, people who are sleeping rough, and the many ‘hidden homeless’. While statistics on the number of people sleeping rough nationwide are not available, a recent count in Dublin found 83 individuals. Of the 8923 adults availing of state emergency accommodation, 6425 (72%) are based in Dublin, while the remainder (2498: 28%) are spread out across all other regions of the country. Of these adults, 65 per cent are single, and 61 per cent are male. Fifty-three percent of those adults are aged between 25 and 44 years; 28 per cent are aged from 45 to 64 years; 17 per cent are aged from 18 to 24 years; and just 2 per cent are aged 65 years or over. The majority of adults in state emergency homeless accommodation (60%) are staying in private emergency accommodation (this includes hotels, Bed & Breakfasts, and other residential facilities). But a sizeable proportion (38%) are also in supported temporary accommodation (accommodation with onsite professional support). Just one per cent of this group are in temporary emergency accommodation, which has minimal or no support. Forty-three per cent of adults in state emergency homeless accommodation in Ireland today are not Irish citizens, with 23 per cent of this group comprising citizens of the European Economic Area (EEA), or the UK, and 20 per cent comprising of non-EEA citizens. Homeless services are provided across nine different regional administrations, with one local authority in each of these regions the 'lead authority'. Each region also has a Joint Homelessness Consultative Forum which are made up of representatives from relevant state and non-governmental organisations which are involved in the delivery of homeless services in their region. (Department of Housing, Local Government and Heritage, 2023).

1.6.3 People with mental health challenges

There is a dearth of data on mental health and mental health services in Ireland. It is not known exactly how many people experience mental health issues, or avail of different types of mental health services. Research suggests that anywhere from 9 per cent to 63 per cent of the adult population in Ireland have personal experience with mental health, with values between 13 and 19 per cent generally appearing most often (European Commission, 2023; O'Doherty et al, 2020; OECD, 2018; Department of Health, 2015). However, rates of mental health problems in Ireland are said to be higher than international averages, with one study finding that Ireland had the third-joint highest rate out of 31 European countries (OECD, 2018). The parameters of 'mental health problems or disorders', 'psychological conditions' or 'personal experiences with mental health' in Ireland differ across literature but in their narrowest terms include depression or depressive disorders, and stress and anxiety, which are the two most common mental health issues in Ireland. In their broadest conceptualisations, they include disorders such as schizophrenia, insomnia, and alcohol use disorder (Hyland et al, 2022). Certain socio-demographic characteristics or conditions have been found to lead to greater risk of mental health problems in Ireland. These include being unemployed or unable to work due to illness or disability and, connected to this, low household income. They also include factors such as being a woman, being middle-aged or older, being separated, divorced or widowed, or having a low level of educational attainment. Recent research has found that just 47 per cent of those experiencing mental health in Ireland sought professional support. Of this group, they are most likely to seek help from their GP (27%), with much fewer seeing a psychologist (12%) and fewer again accessing psychiatry services (10%) (European Commission, 2023). Most mental health services in Ireland are publicly funded, and community-based which means most people are seen in outpatient settings, in day hospitals or days centres, or in their own homes. A small proportion receive in-patient treatment. The HSE have a number of specialist mental health services and programmes aimed at specific populations, such as adults with intellectual disabilities, children and adolescents, older people, and pregnant women, This is in addition to those services targeting specific conditions or health statuses such as severe and enduring mental illness and complex needs, dual diagnosis and early intervention psychosis. Non-governmental organisations (NGOs) play an important role in service provision and mental health promotion in the community and many receive HSE funds to support their work

1.6.4 Migrants, minority ethnic and Roma

Just under 14 per cent of the population in Ireland are foreign-nationals, the largest proportion of whom are from Poland (15%), the UK (13%), Romania and India (7% each), Lithuania (5%), Brazil (4%), Spain and Latvia (3% each). There are 96,000 Ukrainian refugees in Ireland (Central Statistics Office, 2023a) and over 25,000 International Protection Applicants (Department of Children, Equality, Disability, Integration and Youth, 2023). Of the total number of those who came to Ireland between April 2022 and April 2023, 53 per cent were aged between 25-44 (Central Statistics Office, 2023b). Data from 2016 shows that the largest proportion (17%) of non-Irish nationals live in Dublin City (Central Statistics Office, 2016). Just under 3 per cent of those who are resident in Ireland have low English language proficiency. Despite having similar levels of education and employment rates as Irish citizens, the median income is lower for foreign-nationals, while poverty rates, and risks of poverty are much higher (McGinty et al, 2018). In terms of ethnic minority groups, Ireland comprises; 2 per cent Indian, Pakistani or Bangladeshi; almost 1.5 per cent Black; 1.4 per cent Asian or Asian-Irish; and almost 1.3 per cent of other ethnic groups. It is estimated that Roma people make up 0.3% of the population in Ireland. Of this group, the largest proportion are Irish citizens (28%), followed by Romanian (22%), Italian (10%), or Polish (9%) citizens, with many individuals also coming from Czechia and Slovakia. Over half of the Irish Roma population is aged either between 5 and 14 years, or between 30 and 44 years (Central Statistics Office, 2022). Under 3 per cent of the general population in Ireland report having experienced discrimination based on their race, skin colour, ethnic group or nationality when, primarily, accessing services including, but not limited to, education, housing, public or health services (Central Statistics Office, 2019). While data on Roma marginalisation is unavailable, it is known that Roma can experience higher rates of exclusion, discrimination, and racism (Department of Justice and Equality, 2017). Everyone who is ordinarily resident in Ireland is entitled to a range of public health services either for free or for a reduced cost; this of course includes migrants. The HSE’s National Social Inclusion Office aims to reduce health inequalities among migrant, minority ethnic, and Roma (amongst others). A minority of specialist services for these groups are provided directly while most are delivered indirectly through non-governmental organisations which receive HSE funding (HSE, no date (b)).

1.6.5 The Traveller Community

There are approximately 33,000 Travellers in Ireland which accounts for just 0.65% of the total population. The age profile of Travellers is much younger than the wider population, with an average age of 27 years compared to 39 years for the total population. Galway City, Longford and Offaly had the largest resident Traveller communities. Approximately, 92 per cent of Travellers live in permanent (bricks and mortar) housing, while 8 per cent live in caravans, mobile homes or other temporary accommodation (Central Statistics Office, 2022). However, census data from 2016 found that 39 per cent of Travellers are living in severely overcrowded accommodation, compared to 6 per cent of the total population (Central Statistics Office, 2016). This means that a significant proportion of Travellers are experiencing ‘hidden homelessness’ and are thus overrepresented in rates of homelessness (Harvey, 2021). Just 67 per cent of Travellers report ‘good’ or ‘very good’ health (compared to 83% of the total population). According to the most recent and comprehensive data on Traveller health (the All Ireland Traveller Health Study, 2010), mortality rates for Travellers are four times the rate for men in the general population, three times the rate for women, and 3.5 times the rate for infants. Correspondingly, there is a life expectancy gap of 13.4 years

(15.1 years for men, 11.5 years for women) between Travellers and the total population. Fifty-nine per cent and 63 per cent of Traveller men and women respectively reported bad mental health for one or more days in the preceding thirty, compared to 24 per cent and 20 per cent of the wider population. Suicide rates among Travellers were found to be six times higher (AITHS, 2010). There are several Traveller Health Projects and Resources which the HSE's National Social Inclusion Office either fund or have been directly involved with, including those which address vaccine programmes, mental health, and pregnancy. In addition, it supports the work of HSE Traveller Health Units, which aim to improve Traveller health; respond to the wider structural factors which impact Traveller health; and support mainstream health services in providing care to Travellers. Finally, Primary Health Care for Travellers Projects supports Travellers to become community health workers (currently 300 employed nationally: HSE, 2022) to allow primary health care to be developed based on the values of the Traveller community (HSE, no date (c)).

1.7 Public and Patient Engagement Context in Ireland

This section presents a brief overview of some of the recent developments in policy and organisational practice regarding public and patient engagement and service involvement in Ireland, outlining the broader context within which this research study takes place.

1.7.1 Engagement Specific and Population Specific Guidance

The *'Better Together: Health Services Patient Engagement Roadmap'* is the most recently published document in the area of service involvement (HSE, 2022b). Developed by the HSE Operational Performance and Integration Team (HSE, no date (d)), the *Better Together Roadmap* aims to provide a cohesive, consistent approach across healthcare services to public and patient engagement, seeking to establish a shared understanding of what engagement means. Presenting checklists, tools and resources it sets out to build capacity among healthcare staff. As well as outlining the four degrees of engagement as being to inform, consult, discuss and deliberate and collaborate, the Roadmap points to six essential components: (1) commitment to engage; (2) assessing readiness; (3) communication; (4) what to avoid; (5) building in evaluation; (6) training and education. The Roadmap also sets out three different healthcare levels at which patient engagement can/should occur: individual health and healthcare level; healthcare service design, delivery and evaluation; and healthcare policy making level. While not expressly focusing on those who encounter marginalisation, the Roadmap does reference supports to assist in engaging with these populations. In addition, local social inclusion offices are listed on a checklist for conducting meaningful engagement, and helping to support the recruitment of diverse and inclusive involvement samples.

Within the HSE's programme for health services change, *People's Needs Defining Change – Health Services Change Guide* presents a change management policy framework that is driven by engagement (HSE, 2018). This is in terms of emphasising the need to harness the views of those who use services to inform service design and development, and in terms of providing guidance on working with service users, families, citizens, communities and staff to instigate change initiatives. Central within this engagement is a commitment to co-production and power sharing, and the development of engagement processes that include: identifying and mapping connections; understanding key stakeholders; tailoring engagement to groups; planning and engaging with a purpose, and developing and sustaining communication and engagement. The Guide presents guidance around supporting involvement, selecting methods of involvement, and establishing terms of engagement.

There have also been other policy and practice documents related to engagement, but in the main these are not recent, or are focused on distinct service programmes. In the case of the former, this includes the *National Healthcare Charter* of 2012 and the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*. While the active involvement of those who use services was a critical component of the Charter, the Strategy set out seven goals of involvement, including: the need for commitment and leadership; a link between involvement and performance and development; and the need for specific work with socially excluded groups, among others (HSE, 2008). In terms of the latter, the National Screening Service (NSS) developed *'The Patient and Public Partnership Strategy 2019-2023'*. Committed to the empowerment of patients and public, the Strategy identifies three strategic areas for development, comprising: (1) empower patients and the public to play an active role; (2) embed partnership working; (3) strengthen accountability, assurance and learning. The Strategy also emphasised the need to ensure representation from marginalised groups within engagement activities, and decision making.

Policies solely dedicated to public and patient engagement do not exist in the Irish context for any of the study groups. However, the National Social Inclusion Office produced a paper to inform the Office's involvement service user consultation, and the development of related frameworks. This paper identifies barriers and enablers of engagement and participation, and summarises some of the methods and population-specific dimensions that may need to be considered (2023a). Outside of this, recognition of the importance of active collaboration is emphasised across general strategies (and their objectives) targeting some of the different populations, with some documenting specific actions and measures regarding engagement in services. In some cases, references to service involvement within these strategies are explicit in terms of public and patient engagement terminology. In other cases, involvement references are linked to established approaches within the population communities, such as co-production, partnership and/or community development. Generally, across these strategies, there is some recognition on intersectional positions that illustrate the overlap between the population groups.

For those who use mental health services, there is a proliferation of strategies and plans that reference engagement. The *'Sharing the Vision'* policy (Department of Health, 2020) and its *Implementation Plan 2022-2024* aims to enhance the provision of mental health services in Ireland through a shared commitment to working in partnership with those who use services and their families. As such, and extending the principles of the previous policy *'A Vision for Change'*, Sharing the Vision outlines the need for co-production, greater levels of engagement and the role of peer-led and peer-run community development projects in securing better health and social inclusion outcomes. In 2016, the National Mental Health Reference Group (an independent reference group of those who use services, family members and friends) also published *Partnership for Change*, a document detailing recommendations on the structures and mechanisms for 'service users', family member and carer engagement. The HSE's *National Framework for Recovery in Mental Health* (2017) centred on engagement for recovery-oriented mental health services, with two of its principles focused on lived experience (Principle 1), and co-production between all stakeholders (Principle 2). Furthermore, the *Mental Health Commissions Quality Framework* (2023) states (in Standard 1.3) that the mental health service values and actively seeks feedback from service users by, for instance, auditing the experience of service users, family members and carers across the continuum of care and planning services in consultation with service users and other key stakeholders. A key theme of the framework is a compassionate, holistic, non-discriminatory, and person-centred service responsive to the needs of the service user.

Building on a series of partnership endorsing initiatives and strategies, such as the *'National Traveller and Roma Inclusion Strategy 2017-2021'* (NTRIS), the *'National*

Traveller Health Action Plan (2022-2027)' (2022a) sets out to *'Improve Travellers' equality of access, participation and outcomes in mainstream health service through a human-rights based approach'*. Calling for partnership working within local, regional and national health-related structures, the Plan looks to improve the involvement of Travellers in decision-making relevant to Traveller health. For those who use drugs and alcohol, the strategy *'Reducing Harm, Supporting Recovery: a health-led response to drug and alcohol use in Ireland 2017-2025'* seeks to enable participation of both users of services and their families as one of its strategic objectives (HSE, 2017a). Emphasising again the need for multi-level involvement, the Strategy specifies actions regarding the involvement of those who use drugs and alcohol in their own care planning, in improving services and in decision-making structures. Generally, references to service involvement and public and patient engagement are less evident within strategies and plans focused on the remaining two population groups. With respect to homelessness, following the *'Lisbon Declaration on the European Platform on Combatting Homelessness'* (2021), both the *'Youth Homelessness Strategy 2023-2025'* (2023) and the *'Housing for all: Housing plan for Ireland'* (2021) welcome the involvement of all stakeholders in the design and implementation of policy and practice measures. *Housing for All* also stipulates the need for an Inclusion Health approach, which emphasises the need to enhance the participation of those who use services in service involvement and service development. The forthcoming framework document on the *'The Health of Persons Experiencing Homelessness in Ireland: A Strategic Framework (2023-2026)'* is also expected to expressly valorise engagement and involvement by those with lived experiences of homelessness. Finally, in addition to the NTRIS with respect to the Roma community, the *'Migrant Integration Strategy 2017-2021'* generally called for greater involvement of migrant individuals and groups with respect to issues regarding integration. This included the stated need to introduce initiatives for enhancing representation of these communities in key decision-making fora. The *Second National Intercultural Health Strategy 2018-2023* is similarly guided by several principles one of which is the facilitation of 'meaningful service user involvement' in the design, delivery and evaluation of services.

1.7.2 Sector-wide strategies, plans and guides

Existing developments in public and patient engagement within the health and social care system in Ireland are couched within a broader and extensive landscape of other strategies, plans and programmes. At the broadest of levels, and not always in explicit terms, public and patient engagement is generally considered to be espoused within the objectives and principles of a series of all-system approaches and strategies that are currently directing health and social care policy and practice in Ireland. This includes the *Sláintecare* reform programme which aims to transform how healthcare is delivered in Ireland and serves as the overall strategic framework to which many other strategies and plans attempt to align. With principles focused on ensuring 'engagement' and that the 'patient is paramount', public and patient engagement strategies have been linked to, and are likely to be increasingly used within action plans and individual implementation projects, including within the *Sláintecare 2023 Action Plan*. It includes the *'Healthy Ireland Framework'* (HSE, 2013), and its *'Health Services Healthy Ireland Implementation Plan 2023-2027'* (HSE, 2023b). Both documents underpin the drive for active stakeholder engagement across related services and programmes – such as the need for implementation metrics around engaging those using services, such as *'Making Every Contact Count' (MECC)*. All-system approaches also includes the *'Health Services People Strategy 2019-2024'* (HSE, 2019a). In accordance with a broader HSE priority to strengthen confidence in the organisation, the Strategy strives to partner with service users and local communities as well as service providers and other stakeholders to optimize the whole health system.

There are also plans that demonstrate more explicitly longer-term efforts to enhance engagement and constructive communication with patients and the public. This includes the *'HSE Corporate Plan 2021-2024'* (HSE, 2021), in which 'Enabler 1' aims to facilitate the active inclusion of patient, family and carer voice in service improvement. This plan, and preceding HSE corporate plans (from 2008, 2013 and 2018) provide the underlying values of care, compassion, trust and learning for not only the current *Better Together Roadmap*, but also for a number of other initiatives within this area. The Plan, which sought to inform a programme of change and improvement within health services, also served as the basis for the *'Values in Action'* behaviour and cultural change programme that sets out to embed the HSE core values within how staff engage with one another, and with patients and the public (HSE, no date (e)). The growing focus on public and patient engagement is closely intertwined with strategies and plans aiming to enhance the safety and quality of experience for patients. This is exemplified by the *'Patient Safety Strategy 2019-2024'*, where there is a commitment to *'…empowering and engaging patients to improve patient safety'* (HSE, 2019b; p. 10). With a focus on building an open culture of authentic patient-partnership, the strategy sets out a series of actions that support patients being informed and engaged, having the right skills, information and knowledge, and having opportunities to contribute to the design, delivery, evaluation and improvement of care. 'The *Better Together Roadmap* also aligns with the *'National Healthcare Communication Programme'* (NHCP (HSE, no date (f)) and its implementation guide (HSE, 2023c). The NHCP, which again utilises the core HSE values, aims to support staff to take a sensitive and patient-centred approach to engaging with patients and their caregivers – thereby improving the quality and safety of the patient experience. The NHCP and its training modules foster many of the principles associated with good engagement. Finally, the Framework for Improving Quality in our Health Service (2018) aims to orient healthcare planning towards more proactive service improvement, and identifies 'person and family engagement' as one of the six drivers to nurture a culture of ever-improving quality care.

At the level of the individual, the new Assisted Decision Making (Capacity) Act 2023 underscores the right of every person in Ireland to make decisions about their own health and personal welfare (amongst other aspects of their lives), even when this may appear challenging for some people. Key principles of this law support involvement processes, particularly for those who may experience marginalisation. These include: that each person has the ability to make decisions about their own life; and that what some may perceive as an unwise decision does not mean a person is unable to make a decision (Irish Statute Book, no date).

Across these strategies, plans and programmes, while there is some consideration regarding health and social care services for the five groups, there is not a specific focus on public and patient engagement and these populations.

1.7.3 Engagement Structures, Initiatives and Roles

There have also been investments in structures and initiatives that either directly or indirectly support public and patient engagement within the HSE, and more generally within the health and social care system. Under the *HSE Operational Performance and Integration Team* (and formerly linked to the *National Quality Improvement Team* (HSE, no date (g)), there are a range of these programmes and activities. Within this stream, the *'National Patient Forum'* was established by the Quality Improvement Team in 2015 to serve as the first point of contact and act as a sounding board for implementation of new and existing national programmes. It comprises patients, family members, carers, and representatives of advocacy groups. The *'National Patient Representative Panel'* was established in the same vein, with the aim of embedding the views and experiences of people who have used health services at the heart of the design, planning and delivery of health services (HSE, no date (h)). Described as *'Patient Involvement Partners'*, members of the Panel work across a range of projects and diverse areas in the health services, and have in the past contributed to the development of services, standards and training programmes. Other initiatives aligned with the Operational Performance and Integration Team include the Patient and Public Partnership Conference 2023 – aimed at exploring how the HSE works in partnership with patients and members of the public to design and deliver person-centred care - and *'Listening Reports'* which capture and represent patients' perspectives on how health services work or do not work for them. Other structures designed to capture and build on lived experience within the health and social care system include the *'National Care Experience Programme'*, which was established in 2019 as a joint initiative between the HSE, the Health Information and Quality Authority (HIQA) and the Department of Health. The Programme coordinates a series of annual surveys in order to improve the quality of health and social care services in Ireland including inpatient experiences (HSE, no date (i)).

Organisational structures relevant to some of the groups within this study are also evident. The HSE Mental Health Engagement and Recovery Office – a collaborator on this research study – was established in 2019 and seeks to ensure that the voice of those who use services, family members and carers inform the design, delivery and evaluation of services. This work includes: developing structures, systems and mechanisms that incorporate lived experience in service development; promoting partnership between all stakeholders to enable better practices; and promoting best practice in engagement and recovery. The work of the national Office is also supported by local *'Area Leads'* embedded in each of the Health Regions Mental Health Management Teams. Each local Area Lead is tasked with consulting and representing the views of those using services, their families and their carers, as well as developing structures that facilitate the involvement of those with lived experience in mental health services . The Mental Health Engagement and Recovery Office's Strategic Plan 2023-2026 (2023d) has five objectives, which focus on co-production for improved systems, structures and services. The Office also provides general supports for Peer Support Workers – mental health professionals who draw on their own lived experience of health and recovery to support others. In January 2023, there was, for the first time, a formalisation of the Peer-Support Workers for mental health services within the HSE's occupational grade and pay scales.

In terms of social inclusion populations, there has not been an establishment of a similar office with a remit to support public and patient engagement for these groups. However, the HSE National Social Inclusion Office does aim to enhance and advocate for the participation of socially excluded communities across the different dimensions of health services, including planning; design; delivery; monitoring; and evaluation. More generally, and as a part of the National Service Plan (HSE, 2023e) the role of *Patient and Service User Engagement Officer* was introduced in each of the CHOs within the HSE as partnership leads. These roles are tasked with developing and supporting engagement activities for the general catchment population within each of these areas. Finally, an Assistant National Director in Patient Engagement has also been appointed with the HSE.

2. Methodology

This chapter presents the methodology for the research study. It begins with a description of the study design, outlining the key facets of the research approach. Each of the research work packages (WPs) are then described, along with the data-collection methods used in each WP.

2.1 Study design

The study design incorporated three components. First, the research was designed to account for perspectives from the multiple levels within the Irish health and social care ecosystem that are implicated in policy and practice related to involvement (McMillan, 2019). The study targeted key informants at the national and strategic level, the level of service coordination and service provision and, critically, the level of the individual who uses service from the five groups. Gathering together the multiple stakeholders that can impact, and be impacted, by service involvement allowed the research team to contrast the different experiences and understandings on this topic operating within the care system. Drawing together these perspectives and identifying similarities and differences is both a required and valuable feature of this study.

Second, given the multiple sets of informants in this research, and to help embed the voices of those with lived experience within the research design, the research team drew on aspects of a participatory voice-led approach to guide the study (Walsh et al., 2022; Fitzgerald and Walsh, 2017). The approach helps support harnessing different forms of knowledge and the inclusion of groups who can encounter disadvantage within multistakeholder health research processes. It helps foster shared understandings of complex challenges and the sort of solutions that might be required to address them. Within this approach value is placed on the influence of social context, the importance of life-course experiences, the promotion of marginalised voices, and the need for ethical engagement. In addition to guiding the overall ethos of the research design, the approach informed two parts of current research. First, the establishment of the Project Advisory Board, which included representatives from each population (see section 1.3), facilitated an early embedding of a lived experience perspective into the study's governance (Greenhalgh et al., 2019), providing feedback on the research aim, and informing key elements of the research process (including participant recruitment strategies, and study terminology). Second, it helped inform the selection of specific data-collection methods. Consideration was given to including methods that would emphasise the lived experiences of participants, as well as those that would facilitate an equitable multistakeholder discussion of findings and help coproduce recommendations.

Finally, the research employed a mixed-method sequential design, incorporating a range of data-collection techniques and involving both quantitative and qualitative strategies. Mixed-method research has been found to be particularly valuable in health-service research where comprehensive or multi-level analysis is required (Creswell and Clark, 2011). Allowing for a synergy between in-depth, detailed insights and more representative knowledge, mixed-method studies have gained prominence as a means to investigate the level and effectiveness of service involvement initiatives in health and social care settings (e.g. de Freitas et al., 2020; de Grood et al., 2022). They also support interconnected sequential designs, where findings of one method informs the design the next (Malloggi et al., 2020).

With reference to Figure 2.1, the research study comprised of six interconnected WPs, with each WP corresponding to each study objective. These WPs, their data-collection methods and their interrelationship with each other will now be detailed. Data collection for this study was completed from March 2022 to June 2023.

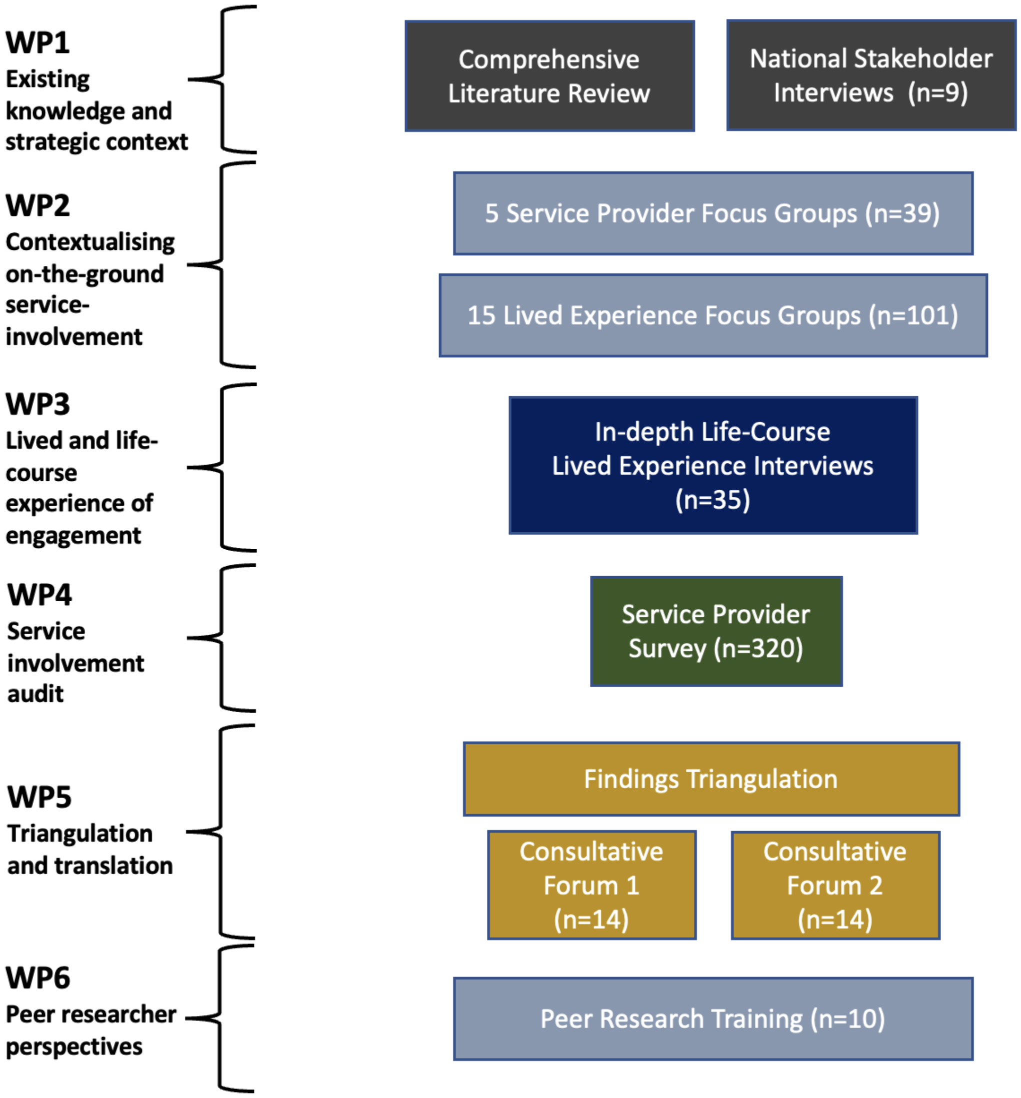

Figure 2.1: Research study design and work-packages

2.2 WP 1: Existing Knowledge and Strategic Context – Objective 1

WP1's purpose was to examine existing research knowledge and to understand the strategic policy, practice and advocacy context of this topic. WP1 comprised of the following two research strands.

2.2.1 Comprehensive literature review

A comprehensive review of international scientific research on service involvement and the lived experienced groups was completed. The purpose of the review was to assess what previous research found, particularly in relation to what does and does not work, and to identify current gaps in knowledge. Although this review was not designed to be a systematised review (i.e. systematic, or scoping review), elements of these methods were incorporated into the design of the review method to ensure a structured and transparent approach. First, a broad research question was developed to guide the review. This was as follows:

> *What is the current state-of-the-art research knowledge regarding how to use service involvement strategies in the design, delivery and implementation of health, social care and mental health services for the population groups in the study?*

The question was used in its generic form to capture material related to populations who can experience exclusion, but was also adapted to specifically target strategies in: (1) health of people who use drugs and alcohol; (2) homelessness health; (3) health of people who use mental health services; (4) migrant, minority ethnic; and Roma health; and (5) Traveller health. The distinction between literature on those who use mental health services and the other groups – where the former is generally more developed – is also acknowledged and drawn out where appropriate. Within the parameters of the research question, consideration was where possible given to approaches and frameworks that have been assessed and evaluated (in broad terms, and not confined to evaluation methodologies). The review approach also recognised the variety of terminologies used in the literature on service involvement. As with this study overall (see section 1.4), the review used *service involvement* as an overarching umbrella term. However, the review also attempted to account for variation in terminologies through the use of a diverse set of keywords and search strategies.

Second, five inclusion and exclusion criteria were developed to guide decisions regarding the inclusion of studies in the review. These criteria included:

1. Publications from 2010 to 2023 on service involvement and groups with lived experience and/or a complete or primary focus on the specific population groups within this study;
2. Publications that present frameworks and approaches which have been evaluated;
3. Publications on research involving pilot studies and case-studies are included, but there was an emphasis on capturing strategies that have been scaled up into mainstream service programmes where possible;
4. Academic peer-reviewed journal articles published in English, and grey literature in the form of research reports;
5. Theses, programme overviews and policy documents are not included in the review.

Third, keywords and database sources were identified and defined for the review. Keywords were derived from relevant social inclusion, intercultural health and mental health literatures, and from review studies related to service involvement (e.g. Greenhalgh et al., 2019). Keywords included social category and group identifiers for each of the populations, service and service development descriptors, and various terms related to involvement. Relevant electronic bibliographic databases for academic peer-reviewed journal articles and research reports were accessed and searched through the search interface facilities available through the University of Galway’s Library Services. Databases were selected based on their relevance to the topic and to social and health sciences. Literature searches were also completed using Google Scholar given its coverage of broad research publications.

Fourth, search returns were reviewed at the level of publication title, publication abstract/executive summary and, when eligible, full text. A manual search of the reference lists of key studies was also completed. These combined approaches identified 247 articles on service involvement for lived experience populations for inclusion in the review. Information on frameworks and approaches, the level of development, and enablers and barriers were extracted from these articles. The findings of this review are presented in Chapter 3 (material specific to the populations), and in Appendix 2a (broader literature on involvement and engagement). The full bibliography supporting the review is presented at the end of the report along with other references cited throughout the document.

2.2.2 National-level Stakeholder interviews

Nine in-depth interviews were conducted with national-level social inclusion, and health and social care stakeholders (e.g. those working in national health and social care service programme implementation, national policy making and national advocacy). The purpose of these interviews was to explore the strategic view of service involvement from a policy, practice and civil society perspective – both in general terms, and in relation to the five populations. Interviews examined the role and the potential of engagement as a strategic tool in service design, planning and evaluation. Stakeholder participants comprised of seven women and two men, and included those working across the HSE, policy units within government departments, interagency taskforces and civil society organisations. Interviewees ranged from those with remits focused on the broad area of Public and Patient Engagement, to social inclusion, to operations and health service implementation and planning. Interviews were conducted online (via Zoom and Microsoft Teams video-telephony platforms) and were based on a semi-structured interview guide. Questions within this guide covered topics such as: (1) the meaning and goals of engagement in health and social care; (2) enablers and barriers of involvement; (3) role of involvement in services for the lived experience populations; (4) current efforts and developments regarding Public and Patient Engagement within the health and social care system; and (5) future priorities. Interviews were recorded and transcribed, and on average lasted for 44 minutes. The analysis of transcripts followed an inductive thematic approach (Braun and Clarke, 2006), where a general coding structure was first developed from the initial reading of transcripts. The coding structure was discussed and agreed amongst the research team and refined iteratively through the analysis process. NVivo 12 qualitative analysis software was used to support this process. The findings of the stakeholder interviews are presented separately within Chapters 4 and 5 as one of the study informants' perspectives, and integrated thematically with the findings from other research strands within Chapter 6

2.3 WP 2: Contextualising On-The-Ground Service-Involvement – Objective 2

2.3.1 Focus group discussions

Twenty focus group discussions were conducted to explore on-the-ground, multi-stakeholder views of service involvement in relation to health and social care services for: (1) people who use drugs and alcohol; (2) people who have experienced homelessness; (3) people who use mental health services; (4) migrant, minority ethnic; and Roma; and (5) Travellers. For each target population, one focus group discussion with service providers, and three focus group discussions with those who use services were completed. There were as such four discussions dedicated to each of the population groups. This meant five groups were conducted with service providers overall (n=39 people; on average 8 people per group), and 15 groups were completed with those with lived experience overall (n=101 people; on average 7 people per group).

2.3.2 Service provider focus groups

The service provider focus groups included representatives of service providers from public, and community and voluntary organisations within the health and social care system, and from across Health Regions. Generally, the participant sample incorporated service coordinators and managers, and frontline service providers and support workers, from clinical, primary and social care teams across mainstream and specialised services relevant to each population. The focus groups also included representatives of organisations who support service access and engagement for the groups. Participants were recruited through open and targeted calls distributed through the national networks of partner organisations of the HSE National Social Inclusion Office and the HSE Mental Health Engagement and Recovery Office. A semi-structured discussion guide was developed to support the completion of the focus groups. Informed by WP1 findings, the guides addressed five core topics: (1) good and effective health, social care and mental health services; (2) meaning and goals of service involvement; (3) existing and successful strategies; (4) enablers and challenges of service involvement for the population of interest (structural; organisational; individual); and (5) future expectations and priorities. To maximise participation and geographic coverage, all provider focus groups were held online via Zoom.

2.3.3 Lived-experience focus groups

For the focus groups with each of the five populations, different sub-groups were targeted within each population. This strategy was employed to maximise the diversity of each of the population samples included within the study, and to reflect variation in service needs, and the degree of exclusion encountered by the different sub-groups. Consideration was also given to the geographic spread of the focus group discussions. The selection of the population sub-groups was guided by the research study's Steering Committee and their experience in supporting each of the populations. The selection was also discussed with the Project Advisory Board, and was in line with the international literature regarding diverse and at-risk sub-groups for each population (e.g. O'Donnell et al., 2016; Ocloo et al., 2021). The sub-group breakdown was considered in tandem with the sample for lived-experience individual interviews in WP3 (see 2.4 for further information). Table 2.1 presents the list of sub-groups included and the total number of participants in each discussion. Participants were recruited through a variety of means, including: by word of mouth and snowball sampling; through representative associations, networks and local community groups; and with the assistance of specialised HSE services, or representatives of community and voluntary organisations who participated in the service provider focus groups.

The discussion guide for these focus groups covered similar topics to those explored in the service provider discussions, but concentrated on gathering lived experience insights of services and service involvement. Short vignettes were also developed to illustrate examples of engagement anticipating that some participants may not have knowledge/experience of such activities. These vignettes depicted scenarios ranging from consultation (e.g. once-off feedback survey) to care planning (person-centred repeated meetings), to co-production (time limited service development project) and strategic level forms of involvement (board and committee membership). Questions were used to probe on the groups' views of the value of these examples, what barriers might impede engagement and what facilitators might help support engagement. Focus group participants were asked if they would prefer to take part in an on-line or in-person focus group. Five focus groups were conducted online (via Zoom), and ten were conducted in person. Eight of the focus groups were conducted in Dublin, while seven were completed across the west, north west, midlands and south east of the country.

Table 2.1: Breakdown of lived experience focus groups discussions

Discussion Code	Study Population	Sub-Population	No. of

	Group		Participants
FG.PWLE.MH.DV	Mental Health	Community-based peer support	12
FG.PWLE.MH.SE	Mental Health	Severe and enduring mental illness	5
FG.PWLE.MH.CA	Mental Health	Child and adolescent mental health	9
FG.PWLE.HO.SH	Homeless	Supported housing	10
FG.PWLE.HO.TA	Homeless	Temporary accommodation	7
FG.PWLE.HO.RS	Homeless	Rough sleeping	4
FG.PWLE.MM.RO	Migrant, Minority Ethnic and Roma	Roma	6
FG.PWLE.MM.DP	Migrant, Minority Ethnic and Roma	Direct provision	6
FG.PWLE.MM.LM	Migrant, Minority Ethnic and Roma	Labour migrants	4
FG.PWLE.TR.GA	Travellers	Galway	6
FG.PWLE.TR.DO	Travellers	Donegal	7
FG.PWLE.TR.DU	Travellers	Dublin	6
FG.PWLE.DA.RE	Drugs and Alcohol	Recovery	7
FG.PWLE.DA.OO	Drugs and Alcohol	Older opioid users	7
FG.PWLE.DA.CD	Drugs and Alcohol	Club drugs	5
Total Number			**101**

2.3.4 Focus group approach, duration and analysis

To help ensure the representation of views across all participants, Participatory Learning and Action (PLA) techniques were employed in each focus group. Based on the work of Chambers (2007), PLA offers practical approaches where power asymmetries may exist. These techniques were designed to bring individual and collective voice into discussions so as to equalize power between groups and/or to provide time for and to encourage each individual to express their views (Tierney et al., 2018; Chambers, 2002). For topic 2 above, a structured individual, ranking exercise was used to explore the perceived role of service involvement in relation to service design, implementation and reform. Participants were presented with five possible outcomes as identified within the literature, and asked to rank them in order of importance and/or add other outcomes they believed should be targeted by involvement strategies. Participants were then invited to discuss their ranking and why they prioritised certain outcomes over others. In the case of in-person focus groups, participants used post-it notes to provide this ranking, whereas those participating virtually used the chat function within Zoom to display their rankings.

On average, service provider focus groups and lived experience focus groups lasted on average for 89 minutes and 79 minutes respectively. All focus groups were recorded and transcribed and were again analysed using an inductive thematic approach (Braun and Clarke, 2006). Analysis for the provider and lived experience focus groups was performed separately, but utilised the same approach. For each set of focus groups, a selection of transcripts was first read independently by two members of the research team. A preliminary coding structure was then agreed for each set of discussions and refined iteratively on the basis of the analysis of the remaining transcripts. NVivo 12 qualitative analysis software was used to support this process. The findings of the service provider focus groups, and the lived experience focus groups are merged with the service provider and lived experience perspective respectively and are presented within Chapters 4 and 5. They are also integrated thematically with the findings from other research strands within Chapter 6

2.4 WP 3: Lived and Life-Course Experience of Engagement – Objective 3

2.4.1 Lived-experience life-course interviews

Thirty-five individual life-course interviews were conducted. Interviews explored in depth the views of service involvement amongst people with lived experience, and how these views were influenced by their life-course experiences of health and social care, and their positions as members of these populations. A secondary purpose was to capture the perspectives of those who were less likely to participate in focus groups, and those who may require very specific sets of services. This consideration again responded to the diversity of the different populations. As with the focus groups, the interview sample was determined by discussions with the study's Steering Committee, but also at-risk groups identified during focus group discussions. Interview participants comprised of 14 women and 19 men, ranging in age from 23 years to 76 years with a mean age of 44 years (SD=years). Table 2.2 presents the breakdown of the interview sample by main population and sub-population group. It also presents biodemographic information for the participants in relation to marital status, education, accommodation and health status. Participants were recruited through the same channels utilised for the recruitment of lived experience focus groups. Eighteen interview participants were from west, north west and midlands regions of Ireland, and 17 were from the Dublin city region. Twenty-three participants lived in a city, while the remaining 12 lived in a town, village or rural countryside.

The interview process comprised of four parts. First, an open participant narration was used to elicit participants' narratives of health and social care service engagement. Adapted from the Biographic-Narrative Interpretative Method (Wengraf, 2001), participants were invited to think about their entire life and to speak about their health experiences in general, without interruption. Second, a life-path exercise (Rowles, 2008; Hägerstrand, 1970) was used as a visual aid to stimulate discussion and to probe on participants' health biographies. Interviewees and researchers worked together to mark down positive and negative factors that characterised people's health and their interaction with the health and social care system on a preprepared timeline. Third, a semi-structured guide was used to explore subjects similar to the focus group topics, and/or those that arose during group discussions. These included: (1) life-course health experiences; (2) good care services; (3) views and goals of service involvement; (4) experiences, barriers and facilitators of involvement; (5) preferences for involvement; and (6) wishes for the future. For topic 4 (experiences, barriers and facilitators), participants were again presented with the engagement vignette examples used in the lived experience focus groups, and asked about their effectiveness and the factors that impeded or enabled each example. Fourth, a short profile questionnaire collected bio-demographic data, including living circumstances, education and occupational background.

Participants chose whether they would like interviews to be held in-person, online, or by telephone. Thirteen in-person interviews, 18 online interviews, and two telephone interviews were conducted. For online and telephone interviews, life-path timelines and vignette examples were forwarded in advance to participants. Interviews lasted between 26 minutes and 107 minutes, with an average length of 71 minutes.

Table 2.2: Lived experience interviewee population groupings and biodemographic information

Population Group	*Those living with mental health challenges*	*Those experiencing homelessness*	*Migrant, minority ethnic and Roma*	*Traveller community*	*Those who use drugs and alcohol*				
	6	8	8	5	8				
Gender	*Male*	*Female*	*Other*	*Don't want to specify*					
	21	14	0	0					
Age	*20-29*	*30-39*	*40-49*	*50-59*	*60-69*	*70-79*			
	4	11	10	6	1	3			
Relationship Status	*Married*	*Cohabiting*	*Single*	*Separated/ Divorced*	*Widowed*				
	5	3	19	6	2				
Educational Attainment	*None*	*Some primary*	*Primary*	*Intermediate/ junior/ group certificate*	*Leaving cert or equivalent*	*Diploma/ certificate*	*Primary degree*	*Postgraduate degree*	*No data*
	1	1	4	3	8	10	4	2	2
Accommodation	*Live with spouse/partner only*	*Live with spouse/partner plus other family*	*Live with family other than spouse*	*Live with others (not family)*	*Live alone*	*Live in Direct Provision*	*Live in temporary accommodation*	*Live in supported accommodation*	
	1	5	9	7	5	1	3	3	
Health Status	*Very good*	*Good*	*Fair*	*Bad*	*Very bad*	*No data*			
	10	14	5	2	1	3			

2.4.2 Interview data analysis

The interviews were audio-recorded, transcribed verbatim, and analysed using an inductive, semantic thematic approach (Braun and Clarke, 2006). First, a provisional coding framework was developed from an initial reading of four interview transcripts by two researchers. This framework was then agreed amongst the team. Second, each transcript was then analysed in an iterative process that sought to merge key elements of the text into descriptive codes, until major inductive themes were identified in each transcript. Third, these themes were used to refine the provisional framework into main themes and sub-themes. To aid this process, descriptive outlines with illustrative quotes were first drafted and discussed for each theme. NVivo 12 qualitative analysis software was used to organise the data. Where appropriate, participant life-paths and exemplar case illustrations were also used to elaborate these themes. Interview findings are presented across all three findings' chapters. The findings are merged with the lived experience perspective presented within Chapters 4 and 5, and are integrated thematically with the findings from other research strands within Chapter 6.

2.5 WP 4: Service Involvement audit – Objective 4

2.5.1 Service provider survey

An on-line survey was developed and distributed to service provider organisations working with or as a part of the HSE to deliver health and social care services to each of the five population groups. The purpose of the survey was to provide an audit of the current level of involvement activity and an overview of the sort of strategies being used within organisations to involve members of the target groups across Ireland. The survey also sought to investigate the views of providers with respect to engagement for these groups on a representative scale, providing an opportunity to further explore findings from the service provider focus groups. The survey was targeted at service managers, service coordinators (or individuals who had a specific responsibility for engaging people who use services) working within organisations, service units or specific service programmes.

The survey comprised of a 51-item questionnaire encompassing six modules of questions. The modules addressed: (1) organisational details (e.g. service remit; size; location; sector; service type; target populations); (2) respondents' personal knowledge, experience and views of service involvement (e.g. knowledge levels; principles and goals of involvement); (3) service involvement in the respondents' organisations/units (e.g. engagement levels; current methods and practices; the timing, nature and purpose of engagement; internal and external supports and barriers); (4) population specific factors related to service involvement (e.g. prioritisation and supports; group/individual challenges); (5) service involvement during Covid-19 (6) views on future directions (e.g. involvement type and focus; suggested good/best practices). The content of these question modules was informed by the findings of earlier work packages – particularly the findings of the service provider focus groups. Questions were also informed by the design and structure of previous surveys of engagement documented within the international literature (e.g. Tripp et al, 2022; Sunderji et al, 2021; Weeks et al, 2017; Cleemput et al, 2015; Tullo et al, 2015). Specific items concerning the level (strategic; operational; individual) and nature (design; implementation; evaluation) of service involvement were derived from this previous work. Consideration was also given to priority areas and goals within key HSE reports and national policy strategies related to service (user) involvement (e.g. HSE, 2010; HSE2008). The development and release of the survey occurred prior to the publication of the HSE *Better Together Roadmap* (HSE, 2022).

Question items consisted primarily of Likert scales and multiple choice/answer items, but also utilised a number of comment boxes to allow for open responses to key topics, and to gather on-the-ground examples of current projects and strategies. A specific item based on the New Economics Foundations Participation Ladder (1999), adapted from Arnstein's (1969) ladder of citizen participants, was also included within the survey. This item provided a brief explanation on each level of involvement (e.g. co-producing; engaging; consulting, etc.) before requiring respondents to highlight the sort of involvement their organisations most often conduct. Each survey included a cover letter describing the aim of the survey and the overall study, and who should complete the survey. The survey was pilot tested with a sample of six respondents, and was estimated to take between 15 and 20 minutes to complete depending on responses to filter items.

2.5.2 Survey distribution

The survey was developed for online administration and distributed using SurveyMonkey, an online platform for creating, sharing and managing data responses for online surveys. Five separate survey links were created, with each targeting service providers linked to the different populations. Considerable overlap was anticipated across the services used by the five groups, but considering each group independently allowed for a more rigorous approach to maximising the coverage of each population.

The distribution of the survey link varied across the five groups. This reflected different data constraints for each group, regarding: the existence of up-to-date service provider lists; and the intended use of any existing provider lists as per GDPR regulations. The final distribution comprised of three core strategies. First, survey links were distributed to complete or partial lists of service providers that were held and could be shared by the collaborating HSE Offices. Second, the survey link was distributed through the network of Health Region regional support teams of the collaborating HSE Offices, who were encouraged to forward the link to their respective service provider contacts within their areas. Third, survey links were distributed on behalf of the research team by group-specific representative organisations and associations. For example, for mental health this included Mental Health Reform and Mental Health Ireland. For Traveller health, this included Pavee Point.

The surveys were initially released for four weeks between September and October 2022. The exception to this was the survey targeting mental health service providers, which had a later release date from October 2022 to November 2022. Two reminder e-mails were distributed at the mid-point and the final week of the release period. It is not possible to ascertain the exact scale of the survey link distribution, and therefore the overall sampling pool. However, based on the number of providers included on HSE held lists and on the third-party distributions lists, it is estimated that at least 500 organisations received the survey link.

2.5.3 Survey sample and survey analysis

Upon closure of the survey, 375 completed surveys had been submitted through the SurveyMonkey platform. Based on platform assessed completion rates and a review of submitted surveys, 55 of these surveys were judged to be incomplete. This left a final sample of 320 surveys. Using the estimated number of organisations that received the survey link as an approximate sampling pool, this final sample would indicate an overall response rate of 64 per cent, but this figure should be interpreted with caution. Table 2.3 presents a breakdown of the survey sample across each of the populations, based on responses to the population specific survey links. It was this sub-sample of organisations that was used as the *provider population group* identifier within the survey analysis. Please see appendix 2A for a discussion of the overlap in the populations served by providers, and for a detailed profile of survey respondents and their organisations.

Survey Group	**Number who completed groups survey link**
Mental health	76
Homeless	74
Migrant, minority ethnic, Roma	23
Travellers	12
Drugs and alcohol	135

Table 2.3: Number of survey respondents by distribution stream

Survey data was managed and analysed using the SPSS 27 statistical software package. After being imported from SurveyMonkey, the data was first reviewed and cleaned, with incomplete or spoiled submissions removed. For the purposes of this report, descriptive statistics including frequency and cross-tabulation statistics were used to analyse the data. Survey results are presented in all three findings chapters and merged with the service provider perspective presented within Chapters 4 and 5. The survey findings are integrated thematically with the findings from other research strands within Chapter 6.

2.6 WP 5: Triangulation and Translation – Objective 5

This WP comprised of two strands. The first strand, which ran in parallel to all of the WPs, sought to synthesise the individual sets of findings and to support the overall interpretation of the research. This involved the integration of analysis, completed for each of the research strands across all WPs, at the level of findings' themes. Guided by the overall aim of the study, shared and divergent themes were noted across the WPs. This integration helped support the keys messages arising from the empirical data collection, and the core research messages of the work.

2.6.1 Consultative Forums and co-production

The second strand involved the completion of two multi-stakeholder Consultative Forums towards the end of the research study. The aim of the Forums was to agree outline priorities and co-produce policy and practice messages based on the findings of the research. These priorities and messages provided the basis for the key development areas and the final recommendations presented in Chapter 8 of this report to enable an inclusive and effective strategy for public and patient engagement for these groups. Therefore, the Consultative Forums helped both support the research translation process and helped agree a shared approach to advancing service involvement for the five population groups.

Each Forum involved a sample of 14 participants (28 people across both Forums) drawn from the service provider and lived experience focus groups. Across the two Forums, there were 12 service provider participants and 16 lived experience participants in all. Participants were selected on the basis of representing different sub-groups, as well as different geographic regions. Expenses and supports were provided for lived experience participants to attend the Forums. The two Forums were held in Dublin in June, 2023.

At each Forum, a brief reminder of the study's aims and methods was first provided. This was followed by the presentation of the research findings in three parts, with 10-minute findings' summaries presented on: (1) meanings and goals of service involvement; (2) extent and nature of service involvement activity; and (3) barriers and enablers of service involvement. After each presentation, participants were given the opportunity to provide feedback and to discuss the findings in small mixed groups (4-5 people) with other service provider and lived experience participants. There was typically two providers and two to three lived experience participants in each of these small groups. During these discussions, each participant was invited to comment on the findings as well as to contribute their own novel observations and suggestions. These observations and suggestions were then fed back into a plenary discussion and were used to distil priority areas and outline recommendations.

Again, to help ensure representation of voice amongst participants, Participatory Learning and Action (PLA) techniques were employed. A short break was provided between each topic, with each Forum taking 3 – 3.5 hours. To help prepare lived experience participants for the sessions, reminders of the research aim and methods were circulated in advance (through short video messages). Audio-recording and note taking were used throughout the two Forums. These materials were used to support the identification of the key development areas and final recommendations presented in Chapter 8.

2.7 WP 6: Peer Researcher Perspectives

In line with the aim of empowering voice to tackle health inequities (Commission on Social Determinants of Health, 2008), two members of each population group (10 people in all) were trained as peer researchers and conducted their own research projects in partnership with the research team. The purpose of the training was to provide these ten researchers with an evidence-based means of promoting their own perspectives, and/or those of their peers, on a topic related to service involvement. Peer researchers were recruited from the focus group and interview participant samples on the basis of representing different sub-group perspectives and geographic areas. The final group comprised of four women and six men from diverse backgrounds, with five people from the east coast of Ireland and five people from the mid-lands and west coast of Ireland. The training programme was based on previous approaches used to support the activation and empowerment of groups of researchers encountering marginalisation (Fitzgerald and Walsh 2016; ICSG 2021) and was designed to be sensitive to a wide range of educational backgrounds and literacy levels. The training comprised of three workshops held in the University of Galway between April and May 2023.

In the first workshop, peer researchers were introduced to the rationale and need for research, the types of research and the need to set research questions. Peer researchers worked in groups of two corresponding to the populations they represented and developed a research question to guide their research project – meaning five research projects were completed in all. These questions were based on four broad themes drawn from the preliminary findings of the other WPs: (1) person-centred and holistic care; (2) trust and respect; (3) inclusive involvement; (4) meaningful engagement.

The second workshop focused on data collection methods, with peer researchers receiving training on photo elicitation and narrative techniques (interviews; auto-experiential approaches – telling their own story). Research ethical issues in general, and those connected with the two methods were also presented and discussed. Peer researchers decided on their preferred method of collecting information, and discussed how they would address their research question using the method. Two of the peer researchers chose a narrative approach. The remaining eight researchers chose photo elicitation, with five people using their camera phone and three researchers using the disposable cameras provided. Peer researchers were given two weeks to collate their narratives, or take five photographs, which they believed addressed their research question. Reminder cards and notebooks were provided to encourage peer researchers to remain focused on their research question, to reflect on ethical considerations when collating their narrative/taking a photo, and to note their thoughts about the process as they went along. The first and second workshops were four hours in length and were held on two consecutive days. The research team also followed-up with the peer researchers during the course of the data-collection to provide support if required.

The third workshop was held three weeks later and focused on research analysis over the course of five hours. Peer Researchers were first introduced to principles of analysis and key analysis approaches regarding the two methods. Peer researchers were supported by researchers from the Irish Centre for Social Gerontology (ICSG) to engage in a reflective process where they identified and discussed with the group how each photograph, or their narrative, addressed their own research question as well as considering how it fed into the broader aim of the study. Contributions from other Peer Researchers also informed their analysis. Peer Researchers' comments were recorded and transcribed. It is these materials that were used together with Peer Researchers' notes to construct short case-studies on service involvement and lived experience for each group. Drafts of each case-study were sent to the Participant Researchers for review. Follow-up telephone calls were then organized to clarify or expand their contributions and to agree key conclusions of their work in conjunction with the research team.

Each workshop used a combination of plenary and project group activities, with a separate member of the ICSG research team working independently with each two-person peer-researcher group. This ICSG team member served as a facilitator for each group and helped the peer researchers work together, and to collect their analysis and interpretations of their final work. The final five case-studies are presented between the remaining chapters of this report. While they did not provide a specific basis for the conclusions of the report, they do provide additional context and insights regarding specific topics that are in line and complimentary to those conclusions.

2.8 Ethics

Ethical approval was received from the University of Galway Research Ethics Committee for this research study. As HSE services supporting specific population sub-groups helped facilitate two focus groups and four interviews for this study, ethical approval was also sought and received from the appropriate HSE Regional Research Ethics Committee. The study utilised a process of informed consent. All participants received study information sheets ahead of their participation in the research. A request for consent to participate was made in advance of data collection, and again on the day of the focus group/interviews. In the case of those participants who used Child and Adolescent Mental Health Services and were under the age of 18 years, all participants and their parents and guardians provided consent for participation. These participants were aged between 14 and 18 years of age.

2.9 Key Messages

1. This study is multi-level, incorporating perspectives from national-level stakeholders, service providers, and people with lived experience from across the health and social care ecosystem.

2. A mixed-method, multi-phase design was employed and involved: a comprehensive literature review; nine national stakeholder interviews; five focus groups with service providers (n=39) and 15 focus groups with lived experience participants (n=101); 35 in-depth interviews with lived experiences groups; an on-line survey with 320 service provider respondents; two consultative forums (n=28); and peer research training (n=10) and projects.
3. The study involves the use of a participatory, voice-led approach, which helps foster the production of shared understandings of complex challenges and the sort of solutions that might be required to address them.
4. Representing the diversity within each of the populations and their different sub-groups was a key objective of the recruitment strategy for lived experience participants.
5. As a part of the participatory voice-led approach, key priority areas and outline policy and practice messages were agreed across a sample of participants and used as a basis for the development areas and recommendations presented in this report.

Peer Research Case Study 1 – Inclusivity in the delivery of drug use services

By Richie Brennan and Carol Fitzsimons

Richie and Carol provide insights into how various types of drug support services could be made more inclusive by involving those who use different kinds of drugs in the design and delivery of programmes. Richie provides photographs, whilst Carol provides interviews with service users and a service provider.

Feeling valued and listened to – *Richie (with editorial support from ICSG researchers)*

This photo is a normal meeting room with a small boardroom table. On appearance you wouldn't think that walking into a room with a table could bring up a lot of feeling. However, on starting to attend meetings for the local Drugs Task Force (DTF), when I entered the room where the meeting was held, I froze, feeling of anxiety, fear, worthlessness, feeling of these professionals are better than … sure I only used drugs, and can't read or write. Panic attacks, sweating, feeling sick. The reason I felt like that when walking into the boardroom relates to my experience of attending meetings in these type of rooms which was always to attend Probation officers or Solicitors appointments. Just never a positive experience up to this point. However, with support from my support workers, who were the main support for me by putting me forward for various training courses, I learned quickly that my experience means a lot and others could learn from what I went through.

This photo shows the roundabout outside the community drug team building. I chose this photo because when I was attending services and explaining what I thought I needed or wanted, it can and did feel like I was going around in circles. Each time you attend a service you feel like you're always explaining your story. You feel like you're not being heard, which can cause you to disengage with other services.

Key message: It was only after attending the community drug team meetings that I felt valued and listened to because they saw me as a person and not just a drug user. I felt my opinion mattered.

Engaging with *all* users of services – *Carol (with editorial support from ICSG researchers)*

Interview 1: *Alice is a 48-year-old heterosexual woman with one adult child who works in a law firm. She has been using and misusing club drugs for 32 years. She has sought help for her issues several times over the past 20 years through her GP and the HSE, only to find that there was nothing available within the service that specifically suits her needs.*

She feels "let down and rendered powerless" due to the fact that anybody she has spoken to within the services seems clueless about "what's going on in her head." What Alice feels she needs "is a designated safe space provided for club drug users where she could feel seen and heard."

Interview 2*: Simon is a 49-year-old heterosexual man with no children and can't hold down a job. He has been using club drugs for 35 years. Over the years he has tried and tried to stop using but anytime he tried to engage with the HSE he came up against a brick wall. He has also contacted the National Drug Helpline several times but to no avail.*

In 2017 he started engaging with the Rialto Community Drug Team. He said "[the drug treatment co-ordinator] is the first professional I've spoken to who seems to know what I'm talking about." Simon attended 8 sessions before he stopped as he "stupidly thought" he had "everything under control." He went on to explain that although he received a great sense of understanding and care, he [also] needed something or some place to go where he'd be amongst his peers and where a decent after care programme was in place.

Conclusion – Richie and Carol

*My photos **(Richie)** back up the research question by illustrating the importance of listening to those who use or have used drugs. The community drugs team made me feel valued. It wasn't just tokenism. When I came out of those meetings I felt bullet-proof, my opinions could possibly benefit somebody who was coming up against barriers. I felt proud, a new feeling for me, that people from similar backgrounds to me were going to benefit from my experience. I was definitely more willing to help and engage with projects because my views mattered. Preparing the individual, getting them to see they have great experience to offer as they have been through the different services and can highlight the different gaps, benefits everyone all round.*

*My interviews **(Carol)** highlight how awareness and de-stigmatisation of club drug use needs to be addressed on a national level. There is a whole generation of club drug users who have been cast aside by the services. There's a lack of service provision by the HSE for users. If you ignore something for long enough it will [not just] go away.*

3. Literature Review – Specific Considerations for the Five Groups

For a review of the general literature pertaining to service involvement in health and social care services, please see Appendix 3A. This supporting review covers: the overall development of service involvement; models of involvement in different national health systems; critiques of involvement; and illustrative examples of specific involvement models and measures.

This chapter presents the findings of the review of the international state-of-the-art research knowledge on service involvement strategies in health and social care for the five groups and for other populations who can encounter social exclusion. A brief assessment of the relative state of knowledge on service involvement for each group is first outlined. As a backdrop for some of the group specific topics discussed later in the review, a short overview of complex health and social care systems and their relevance to this topic is described next. The type of service involvement and the state of development of frameworks, pilot studies and scaled up initiatives are then presented for each group. This is followed by a description of shared barriers and facilitators of service involvement that challenge the inclusion of these populations. A review of specific challenges and considerations for each group individually is then presented. The separation of groups in this review masks the intersections between these different populations, and some of the research evidence. Generally, while belonging to several groups who can encounter marginalisation can lead to greater inequality in needs and voice, this is not always directly accounted for within service involvement research (Robards et al., 2020; Shimmin et al., 2017). There is a need for future research to open opportunities for intersectional research on involvement.

3.1 Introduction – Assessing State of Research Knowledge

Some of the population groups included in this research have attracted stronger attention within the international literature relative to others. Work in the area of mental health is most advanced, as demonstrated by the development of co-production tools, assessment frameworks, and recommendations to optimise collaborative relationships within the sector. Research regarding people who use drugs and alcohol has also seen significant growth, with documented examples of in-depth forms of involvement in the development of services becoming more prevalent. Benefits of involvement for both of these populations have been noted to include increased satisfaction and a sense of empowerment, decreased stigmatisation and feelings of exclusion, improved and expanded service delivery, greater likelihood of reaching treatment goals, and more balanced power dynamics between service staff and those who use services (Omeni et al., 2014; Wenaas et al., 2021b).

In contrast, research on service involvement in the areas of homeless, Traveller, and migrant, ethnic and Roma health is generally underdeveloped, with the Traveller community in particular underrepresented within the literature (Cafferty and Collins, 2011; O'Donnell et al., 2016; Andrews and Heerde, 2021). Across these groups, studies for the most part concentrate on efforts to ensure individual-level decision making and regular consultations, emphasising community based initiatives to support involvement activities (Lhussier et al., 2016; Kirwan and Jacob, 2016; McFadden et al., 2018; van den Muijsenbergh et al., 2019; Beaton et al., 2020; Bell et al., 2020; Villani et al., 2021). While there is evidence pertaining specifically to the benefits of peer support workers and advisory boards involving people with lived experience for each population, there is a scarcity of research documenting and assessing co-design and co-production activities for these groups (Van Hout, 2011; De Freitas and Martin, 2015; Dyson et al., 2020; Radl-Karimi et al., 2020; Andrews and Heerde, 2021; Chauhan et al., 2021a; Nash and Arora, 2021).

It is worth noting that across the five population-specific literatures there is in relative terms a reasonable focus on peer work and peer support, with this topic representing a strong cross-cutting dimension of service involvement literatures (Park, 2020a; Barker and Maguire, 2017; Shalaby and Agyapong, 2020; Condon et al., 2022). As such, references to peer work are integrated across many of the sections within this literature review. That said, there is significant variation in coverage across the groups, with a weaker development of this focus within migrant health. Overall, the body of literature on peer work discusses the extent to which peers are embedded in service provision, both in design and development as well as delivery, and how meaningful their contributions can/should be. The specific tasks peers take on are also discussed and include mediation (between individuals and service providers), the provision of social support, and helping manage care or medication regimes. The benefits of peer involvement with the population groups are also set out in these studies and these include: helping those with lived experience feel seen and heard; establishing trust between individuals and communities, and care services and structures; and helping individuals to meet their personal goals and to navigate systems (Park, 2020a, 2020b; Miler et al., 2020; Barker and Maguire, 2017; Mayer and McKenzie, 2017; Shalaby and Agyapong, 2020).

3.2 Complex Systems: Challenges and Opportunities for Service Involvement

Health and social care systems are seen as being problematic to the extent that they are thought to be in crisis and unsustainable, with potentially insurmountable, 'wicked' challenges (Dunston et al., 2009). This is caused by, and indeed causes, complexity in these systems. Connected to this, constant system change creates additional complexities, needs and demands, whether this might be due to factors such as growing rates of homelessness, or increased migration (Frazer et al., 2020; Barry et al., 2018). While it may not be possible to control complexity, it is nonetheless important to recognise the complex contexts within which the health and social care system operates (Baumann et al., 2022).

It has been argued that incorporating the voices of those with lived experience in the design or delivery of services can be challenged by the complexity of care systems (Lloyd et al., 2023). For example, for underserved communities, complexities in systems can be in part responsible for poor service access, and ultimately the needs of the communities not being sufficiently met. These groups can feel disillusioned with the health and social care system and distrustful of actors therein – where people in the system, and the power they hold may influence the extent to which a system can be changed, with a culture of change resistance sometimes being evident (Barry et al., 2018). This can have consequences, therefore, for meaningful engagement with disenfranchised populations who may feel disempowered (Cyril et al., 2015). More broadly, it has been noted that there are challenges around evaluating involvement in complex health systems, either because structures make it difficult to resource evaluation, or because impacts themselves can be complex, non-linear, multi-layered, indirect, or simply not clearly visible (Lloyd et al., 2023). Further, where service change over time, arising from involvement processes, is challenged by the complexity of care systems, and not (sufficiently) felt by those with lived experience, groups can feel discouraged about involvement processes and are unlikely to participate in the future (ibid.).

However, it is also important to note that system complexity, due to its genesis in human action, should not be seen as something which *cannot* be overcome by human actions (Holmes et al., 2017). As such, some research highlights the (potentially) important role for service involvement in tackling complex system reform. It has been argued that meaningful engagement holds the potential to transform health and social care systems (Dunston et al., 2009), and there is growing recognition of its importance for health policy decision-making, particularly at the macro-level (Baumann et al., 2022). In this vein, Donetto et al. (2014)

argue for the importance of valuing small-scale incremental change arising from ‘experience-based co-design’ processes because these can be built upon, incrementally, for wider-reaching transformation. As causal factors can derive from micro, meso or macro levels, it is important to utilise approaches at and across all levels (Frazer et al., 2020), and to have a ‘toolbox’ full of different processes from which to choose (Curry et al., 2020). In addition, gaining multiple perspectives helps understand and address complex health and social care system problems. This is why having the voices of those with perhaps the most different experiences (those who have experienced marginalisation) involved in service design or delivery may be most impactful (Trinkley et al., 2022; Curry et al., 2020). However, it is important that the focus lies not on processes of engagement (as valuable per se) but rather outputs such as policies, and on how policies are practically implemented, and can generate impacts (Baumann et al., 2022).

3.3 People Who Use Drugs and Alcohol and Involvement

3.3.1 Forms of Involvement

There is reasonably active consideration of people who use drugs and alcohol within the international research literature on service involvement. Although review findings indicate that service involvement in this field remains concentrated on person to person (or service) exchanges, evidence of meaningful involvement at an operational and coordination level is becoming more prevalent (Rance and Treloar, 2015; Marchand et al., 2019; Bruland et al., 2021). At the lower to mid-levels of involvement, research has documented involvement in activities such as the administration of satisfaction surveys, education programmes for service providers, and in the operation of a drop-in centres for peer groups (Patterson et al., 2010; King, 2011; Trujols et al., 2014; Goodhew, Stein-Parbury and Dawson, 2018). More advanced involvement examples are also evident and incorporate activities that include engagement in the development of a charter of rights, representation on service decision-making committees, participation in staff recruitment, quality assurance activities, and co-production of services more generally (Laitila, Nikkonen and Pietilä, 2011; Tober et al., 2013; Greer et al., 2016; Goodhew et al., 2018; Bruland et al., 2021; Wenaas et al., 2021b). While a research focus on service innovation with this population is growing (Bakkeli and Grønningsæte, 2020; Park, 2020a), there is as with other groups a lack of evidence regarding involvement in policy and programme development (Ti et al., 2012). Recognition of the benefits of involvement for this population is also growing, such as improved access to effective and safe treatments and support services, and enhanced services (Rance and Treloar, 2015; Alves et al., 2016; Goodhew et al., 2018; Park, 2020a, 2020b). However, although involvement activities tend to be endorsed in policy, commitments still do not always translate into practice (Rance and Treloar, 2015; Rosenberg and Hillberg, 2016; Bruland et al., 2021).

There is a long tradition of integrating peer-based care components within the development of service provision for those who use drugs and alcohol (Park, 2020a, 2020b). While originally grounded on informal practices, these peer support roles have evolved in recent decades as integral elements of the dimensions of the care system relevant to these groups (Fruitman et al., 2022). Nevertheless, tokenism regarding peer engagement is an ongoing concern due to stigmatisation of services and more generally structural forms of oppression (Greer et al., 2019a; Miler et al., 2020). Further, while peer support specialists are a fast-growing workforce, their levels of involvement can differ (Almeida et al., 2020; Miler et al., 2020). Peers are widely represented in support groups, and may engage in peer co-production of services, but are often absent from meaningful power processes and decision making (Greer et al., 2019a; Park, 2020a, 2020b). A survey of peers in the United States suggests that the move to virtual peer engagement, which increased during the COVID-19 pandemic, involved a shift from traditional peer roles such as group facilitation towards more responsible roles in connecting individuals with resources (Fruitman et al., 2022). Similarly, a study involving representatives from policy-making organisations observed that during the pandemic, policymakers shifted from traditional top-down approaches to more inclusive approaches involving co-production of recommendations for drugs and alcohol services (Henry et al., 2022).

3.3.2 Frameworks and pilot studies

Despite the more developed literature on service involvement pertaining to those who use drugs and alcohol, work documenting pilot studies and tools that demonstrate sustained implementation and delivery remain underdeveloped. This includes studies that present evidence of policy frameworks developed to support participation (Treloar et al., 2011; Rance and Treloar, 2015; Rosenberg and Hillborg, 2016). There are a number of critical discussions about how involvement can be conceptualised to inform productive participation for this group. A review of studies in this area recommends that a participation framework needs to be visualised in a more dynamic way than the hierarchy implied by the traditional ladder of participation (Goodhew et al., 2018). Park (2020b) proposes a framework for the conceptualisation of co-production based on a shared understanding of the importance of both expertise and experience. Park notes that one co-production mechanism may not be available or may not work as intended in every service setting, and therefore providers may use alternative or multiple mechanisms to best incorporate needs (2020a, 2020b). Bakkeli and Grønningsæte (2020) develop the *'co-production triangle'* model (see Figure 3.1), in which the relationship between the service provider and the individual is extended to include skilled peers in a mediating role. The three points of the co-production triangle represent a cooperative structure involving those who use services, those who provide services, and skilled peers.

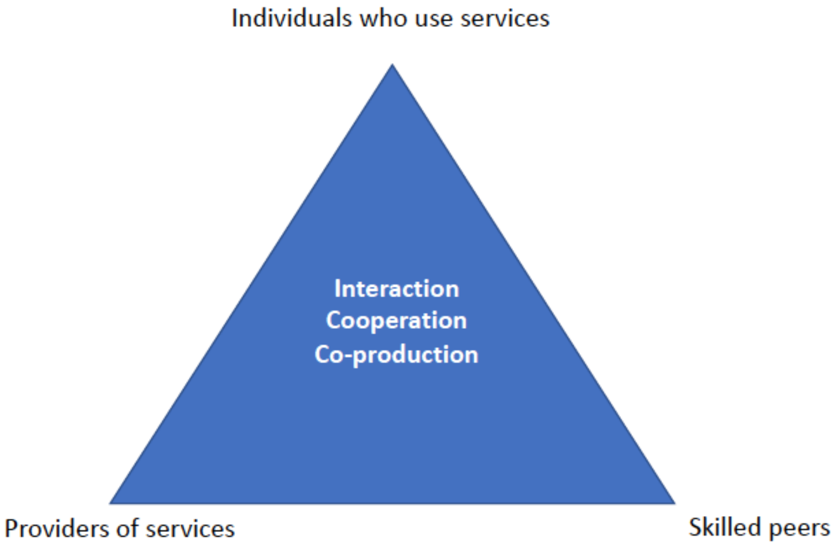

Figure 3.1: Co-production triangle, adapted from Bakkeli and Grønningsæte (2020), p.101.

Recent pilot studies demonstrate evidence for the potential of creative co-production and co-design approaches to improve service delivery for those who use drugs and alcohol. For example, Wolstenholme et al. (2020) used a co-production method involving workshops to identify barriers to clinic engagement and to produce contextually sensitive solutions that included myth-busting posters and postcards, a mobile clinic van, and peer support. The researchers stress the potential for co-production with populations perceived as 'hard to reach', to offer contextually sensitive solutions beyond more traditional approaches such as outreach clinics. In an example of an upscaled intervention (Hogan et al., 2021), a recovery-oriented programme entitled 'Moving On In My Recovery', co-produced and co-facilitated alongside individuals with lived experience, has been implemented with recovery groups in Wales. Participants reported a profound effect on their lives and skills, shown to be sustained in a three-month follow up, along with abstinence rates. The programme was found to be viable for a larger randomised control effectiveness trial (Hogan et al., 2021). However again, as with the other population groups in this study, there is insufficient evidence on the impact and scaling up of service involvement for this group. Therefore, despite the significant advances made for those who use drugs and alcohol in relation to service involvement, ambiguity and uncertainty remains regarding the capacity of service involvement to generate outcomes. Although it has been noted that examples of successes may sit outside the formal evidence base (Ti et al., 2012).

3.4 Homelessness Health and Involvement

3.4.1 Forms of involvement

The relatively low level of work on service involvement with those experiencing homelessness in the international research literature is considered to directly reflect the state of development of engagement activities with this group in practice (Whiteford, 2011; Phillips and Kuyini, 2018; Omerov et al., 2020; Andrews and Heerde, 2021; Horsell, 2022). The research that has been completed concentrates on the opposing ends of the service involvement continuum. Studies document efforts to ensure more routine and basic consultation activities at one end, and research on peers providing support for health-related change at the other. Key areas of focus include accessibility to services, ensuring a trauma-informed environment, the role of service provider attitudes, and the provision of social and peer support (Barker and Maguire, 2017; Phillips and Kuyini, 2018; Kahan et al., 2020; Clifford et al., 2020; Miler et al., 2020). That said, recent empirical work may indicate a shift towards documenting examples of effective co-design in homeless health services. For instance, Donald et al., (2022) report on a co-development process to advance methods for the use of patient- reported outcome measures (PROMS) and patient- reported experience measures (PREMS) with people who are homeless and experience chronic illness. In a study exploring perceptions and experiences related to pregnancy and parenting support among youth experiencing homelessness, Eapen et al., (2022) recommend that interventions should be co-designed with people with lived experience. There is also a notable body of work on models of housing and support intervention for those in homelessness that place service involvement and individual choice at the core of their design, and general approach (e.g. Hansen, 2018; O'Shaughnessy and Greenwood, 2021). Overall, however, there continues to be a lack of literature that presents examples of what constitutes good practice and effective participation for this group, with growing recognition of the need for meaningful involvement in health-related policy making on homelessness (Phillips and Kuyini, 2018; Clifford et al., 2019; Horsell, 2022).

Despite the fragmented evidence base, the benefits of establishing and sustaining a diverse range of involvement strategies with people who experience homelessness has been demonstrated (Andrews and Heerde, 2021). A case study by Ferguson et al. (2011) with youths who experience homelessness suggested that involvement in service programmes can have a number of benefits. In particular, being recognised and validated promoted key developmental characteristics, including independent decision-making and self-sufficiency (Ferguson et al., 2011). This evidence is particularly strong with respect to peer-led programmes. Research has shown how peers can assist in building trust with the homeless community and assist participants to meet goals and navigate systems (Nyamathi et al., 2021). A review of studies in this area with people who experience homelessness found that peer support serves to: act as a buffer for professionals; aid individual health management and medication regimes; reduce hospital admissions and relapses; and increase coping skills and overall quality of life for supported people (Barker and Maguire, 2017). Benefits also include peers' commitment to supporting experience-based relationships, and additionally, benefits for peers' own self-confidence (Barker et al., 2018). Furthermore, there is evidence of positive outcomes of peer-led/peer-staffed interventions at the intersection of homelessness and the use of drugs and alcohol (Miller et al., 2020). Benefits include an overall reduction in drug and alcohol use, improvements in homelessness status, and psycho-socioeconomic benefits (Miller et al., 2020). A number of researchers in this area advocate not only for co-design models, peer workers, and lived experience advisory groups, but also recommend the active involvement of researchers with lived experience to enhance knowledge of relevant service involvement strategies (Andrews and Heerde, 2021; Campbell et al., 2021; Nyamathi et al. 2021; Walsh et al., 2022).

3.4.2 Frameworks and pilot studies

Further research is needed in regard to evaluation of the effectiveness of service involvement programmes for those experiencing homelessness (Phillips and Kuyini, 2018). However, work on frameworks and pilot studies point to evidence of some progress on implementation with some demonstrable signs of sustained delivery found (Barker and Maguire, 2017; Kahan et al., 2019; Beaton et al., 2020; Miller et al., 2020; Abraczinskas, Rumala and Turk, 2021). A number of studies in this area document recent projects to support the needs of those at the intersection of homelessness and domestic and gender-based violence. Abraczinskas et al. (2021) describe how a woman's centre in Los Angeles adopted the Community of Solutions framework, which builds leadership skills for meaningful collaboration, equity and sustainable health improvements, to engage people with lived experience of homelessness. Kahan et al. (2020) examine stakeholders' experiences of a co-produced peer-facilitated psychosocial group targeting female youth experiencing homelessness and gender-based violence. The study highlights the importance of addressing access barriers, providing peer support training, and having resources in place to address disclosures of trauma (Kahan et al., 2020). There is lack of research on involvement in homelessness, which is needed to provide insights in terms of efficiency, effectiveness and influence in service delivery and policy development.

3.5 Mental Health and Involvement

3.5.1 Forms of Involvement

There is a longer history of service involvement in mental health services compared with any of the other populations included in this study, with research evidence correspondingly more developed. In recent decades, mental health services have progressed towards care models informed directly and sometimes led by those who use services (Tambuyzer et al., 2011; Noorani, 2013; Storm and Edwards, 2013; Bee et al., 2016; Freeman et al., 2016; Kennedy, 2017; Laitila et al., 2018). There is now a burgeoning literature describing individual involvement as a fundamental pillar in services (Brooks et al., 2015; Cooper et al., 2016; Brooks et al., 2019; Bell et al., 2021; Fox, 2021; Matscheck and Piuva, 2021; Norton, 2021). Co-design is also emerging across some settings and jurisdictions as a framework to guide service design, implementation and assessment (Mulvale et al., 2016; Hackett et al., 2018; Palmer et al., 2019; Currie et al., 2020; Bevan Jones et al., 2020; O'Brien et al., 2021). The role of experts by experience, such as paid peer support workers, is embedded in involvement processes (Mayer and McKenzie, 2017; Shalaby and Agyapong, 2020; Marks et al., 2021; Lidbetter et al., 2022). Generally, some degree of involvement is increasingly incorporated into the development of mental health services and policies in western developed nations, with policies highlighting the importance of shared decision-making in care planning (Storm and Edwards, 2013; Kennedy, 2017; Laitila et al., 2018; Brooks et al., 2019; Gordon et al., 2021; Pappa et al., 2021). A recent review suggests that co-production is having positive outcomes in recovery colleges, in particular regarding changing power dynamics and practitioner attitudes (Bester et al., 2021). Nevertheless, such policies are not always successfully implemented in practice, with implementation found to heavily depend on organisational and practitioners' buy-in (Grundy et al., 2016; Cooper et al., 2016; Stomski and Morrison, 2017; Brooks et al., 2019; Farr et al., 2019; Higgins et al., 2020; Bell et al., 2021). There are fewer studies documenting the formalisation of collective influence at an organisational level in the planning and development of services (Rosenberg and Hillborg, 2016; Graffigna et al., 2020). Overall, it has been suggested that more studies are needed to understand the implications of co-production as a lived reality for participants (Kirkegaard and Andersen, 2018), more data is required providing guidance on how to practice co-production in mental health services (Norton, 2021), and more tools are needed to evaluate the participation of those who use services in co-production in these services (Gheduzzi et al., 2019).

Despite the advanced nature of service involvement for this population, Trevillion et al. (2022) argue that the views of those who use services have not had the expected impact on the development of mental health care. Studies have shown that while ideologically, service involvement appears to be widely accepted within the mental health sector, it can be the case that the influence of those who use services is not sufficiently nurtured due to organisational cultural narrowness and traditional hierarchical power distribution (Rosenberg and Hillborg, 2016; Kennedy, 2017; Smith et al., 2020; Burgess and Choudary, 2021; Kirwan, 2021; Tindall et al., 2021; Chauhan et al., 2022; Owen et al., 2022). Although employed peer support workers and peer networks are an integral part of mental health care, it seems the potential for redistributing power to those who use services within health care systems is still a daunting prospect (Palmer et al., 2019; Shalaby and Agyapong, 2020; Åkerblom, 2021; Chauhan et al., 2022). Rose and Kalathil (2019) go further and argue that co-production in mental health may in effect be impossible, particularly in the case of those from racialised groups due to historical oppressive structures and epistemological ideas about who produces knowledge and how it is valued. Additionally, a review of the use of co-design methods with culturally and linguistically diverse communities to improve or adapt mental health services finds that there is a lack of understanding about meaningful engagement – with no specific studies using experience-based co-design with culturally diverse communities (O'Brien et al., 2020). People with dementia are also particularly underrepresented in involvement in shaping service provision (Smith et al., 2020). Therefore, as mental health services are increasingly encouraged to implement service involvement, further research is required involving underrepresented communities (O'Brien et al., 2021; Smith et al., 2020).

3.5.2 Frameworks and pilot studies

There are several frameworks, tools and protocols to elicit patients' preferences in mental health care planning and co-production of services, and an increasing body of work documenting pilot studies that demonstrate sustained implementation. Despite challenges in measuring and monitoring effectiveness, some progress is evident (Storm and Edwards, 2013; Gibbons et al., 2014; Bee et al., 2016; Graffigna et al., 2020).

Frameworks like the *'Co-production Compass'* (COCO) (Graffigna et al., 2020) and planning and development tools developed by Mulvale et al. (2021) help elicit individuals' preferences and address imbalances of power in co-production. The *'Co-production Compass'* (COCO) is an analytical framework for monitoring the preferences and meaningful involvement of those who use services in the co-production of healthcare services in mental health settings. With reference to Figure 3.2, the framework involves three organizing themes: shared and practice-oriented evaluation standards; multi-dominion approach (i.e. service co-production; active engagement as an enabling factor; the recovery process); and multi-stakeholder evaluation (Graffigna et al., 2020). The planning and evaluation tools developed by Mulvale et al. (2021) attend specifically to addressing imbalances of power in co-production, through their COMPASS tool. The authors conducted multiple Experience-based Co-design (EBCD) studies with a group of young people with mental health issues to develop a set of tools for navigating issues of vulnerability and moving towards collective power. The COMPASS tool encompasses four main themes (supporting managers, preparing participants, building affinity, and fostering sensitivity) that any team must navigate to address inherent power imbalances in co-production. This multi-actor model focuses on the dynamics of the relationship between the research team and those who use services, service providers, caregivers, and managers in co-design and co-production.

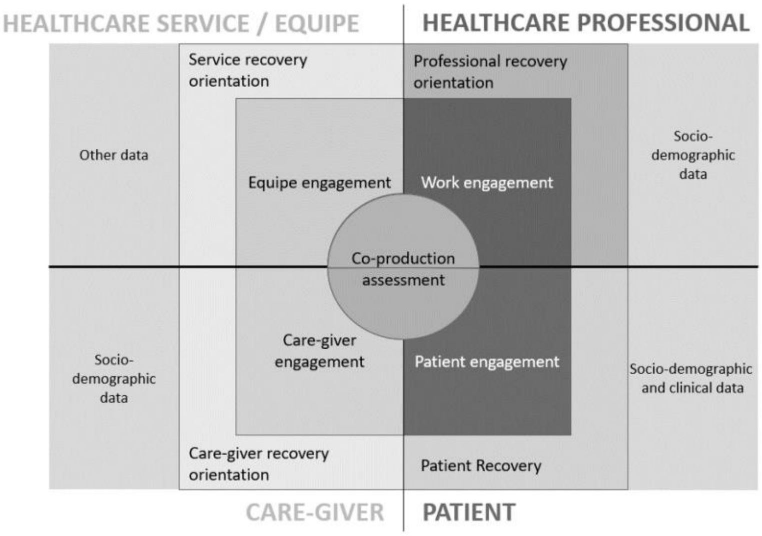

Figure 3.2: Co-creation compass: detailed description of the framework elements (Graffigna et al., 2020, p.7)

Daya et al. (2020) present a conceptual model (Figure 3.3) for welcoming challenging views in mental health research, policy and services. The model describes four broad groupings of diverse experiences and views. The hypothesis that views are influenced by experiences, and that experiences of treatment are distinct from experiences of care, underpins the model and is illustrated by separate axes for treatment and care experiences; these axes intersect to form a matrix with four quadrants. The model seeks to promote a comprehensive approach to authentic co-production practices in mental health, and health systems more generally. It provides for developing awareness of individual and systematic bias, listening to a range of voices and responding to the diversity of preferences. Diverse experiences are organised into a spectrum of differing views about language use, personal experiences, and positions on advocacy agendas. It is argued that the model creates opportunities for individuals to understand their own experience, views, and voice relative to others and advocate for change.

Pilot studies further exhibit the evolution of service involvement within mental health services. For instance, an Irish community development initiative implemented a co-produced arts and music programme, fostering creativity, personal recovery and integration while encouraging shared decision-making (O'Shanahan et al., 2022). The initiative, which involves service users in planning, emphasizes the role of community in care delivery and underscores the importance of trust and reciprocity. Despite the authors stressing the significance of arts for mental well-being, the authors recommend formal mechanisms to compensate contributors.

Involvement in technology-based co-design, like mobile application development and virtual environments, has been an emergent trend (McClelland and Fitzgerald, 2018; Realpe et al., 2018; Ospina-Pinillos et al., 2019; Bevan Jones, et al., 2020; Potts et al., 2021; Zidaru et al., 2021). Bevan Jones et al. (2020) developed a checklist of questions to consider when planning, documenting or analysing co-design in this context. An evaluation of the pilot implementation of a co-designed electronic care pathway tool to facilitate co-production in mental health care planning found that the tool could enable involvement, but streamlining with records was an obstacle (Farr et al., 2019). Therefore, health information technological development is important. Mbao et al. (2021), through a co-design and co-production process, developed a decision-support tool for peer support specialists and those with lived experience to select technologies to support their recovery. They found that the co-design and co-production process was feasible, with the potential to empower those involved, and increase engagement in the use of technologies supporting recovery.

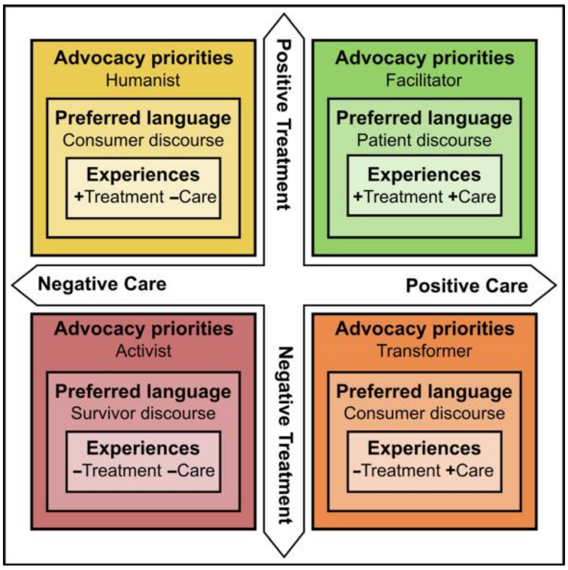

Figure 3.3: Integrated model: Experiences, language, and advocacy priorities (Daya et al., 2021, p.303).

Overall, while service involvement in mental health care is advanced, the field continues to evolve, with a continuing need for further research on the development of evaluation tools and methodologies.

3.6 Migrant, Minority Ethnic and Roma Health and Involvement

3.6.1 Forms of involvement

Research related to service involvement and those from migrant, minority ethnic and Roma backgrounds is concentrated in the areas of individual-level decision making (primarily in terms of access and communication issues) and general consultation activities (Björk Brämberg et al., 2010; MacFarlane et al., 2021a; Røhnebæk and Bjerck, 2021). Societal or system level decision making in relation to these groups receives little attention (MacFarlane et al., 2021a). Research in this field tends to document how these groups are often excluded from policy making forums, rather than presenting examples of meaningful involvement (De Freitas et al., 2014). As with some of the other groups in this study, this reflects the underdevelopment of service involvement practices with groups linked to these communities (Filakovska-Bobakova, 2019; Chauhan et al., 2021a). There is as such a lack of evidence on how to engage meaningfully with diverse ethnic minority populations, despite a recognised need to incorporate diverse voices in participatory forms of involvement (Chauhan et al., 2021a). A review of involvement in maternal care with migrant and ethnic minority populations, for instance, finds low levels of engagement and a lack of systematised evidence about how to tailor strategies to individuals' needs and preferences (De Freitas et al., 2020). Service provider misconceptions and assumptions about individuals' requirements, and issues around capacity, and training regarding taking an active decision-making role in one's own care, are two factors considered to contribute to these broader deficits (De Freitas et al., 2020).

While there is some recent, relevant evidence in terms of co-design in the area of digital healthcare services and tools, and health promotion and information (Bartlett et al., 2021; Seymour-Smith et al., 2021; Bartlett and Boyle, 2022; Power et al., 2022), the literature on co-production and these groups is largely considered generic and fails to account for and/or harness how members of these communities could co-produce differently (Røhnebæk and Bjerck, 2021). In addition, and as indicated by Chauhan et al. (2021b), involvement with these groups tends to be limited in conceptualisation, where links between processes – which need to reflect the diversity of migrant and ethnic populations – and outcomes are poorly conceived. Such knowledge gaps are noted to be especially significant given how the lack of representation of diversity in service involvement processes has been found to exacerbate existing biases experienced by these groups, or to limit the take up of reformed services by these groups (De Freitas et al., 2014; De Freitas and Martin, 2015; Filakovska-Bobakova, 2019; Chauhan et al., 2021a). For meaningful involvement, research has shown that it is necessary to address multiple barriers across diverse communities, including mental and physical health, caring and employment responsibilities, legal status, fears of stigmatisation, and trust (De Freitas et al., 2014; Kirwan and Jacob, 2016; ; De Freitas et al., 2020; Radl-Karimi et al., 2020). Reflecting wider concerns about structural innovation barriers with respect to migrant, minority ethnic and Roma populations, there have been calls for funding bodies, organisations and even research journals to support community-based research and co-produced policy and health services (Gogoi and Armitage, 2021).

3.6.2 Frameworks and pilot studies

A development framework for analysing the enabling and constraining conditions for service involvement amongst migrant and minority ethnic groups is proposed by Røhnebæk and Bjerck (2021). The framework helps in the identification of blind spots in how co-producers from these communities are engaged, and suitable strategies for engagement. Recent case studies demonstrate the centrality of community buy-in for successful collaborative involvement and co-production in health and social care services for those from these backgrounds. While this evidence-base is limited in depth and scope, there are a number of models that aim to embed this buy-in from early stages of service development. The Tallaght Roma Integration Project (TRIP), located in Dublin, Ireland, harnesses community development principles to support the engagement of the local Roma community with service providers for the purposes of highlighting need and mobilising change in service provision (Kirwan and Jacob, 2016). Bartlett et al. (2021), in a co-design case study on digital healthcare tools in Australia with female migrant communities, found that the process led to the successful development of a cultural relevant application for non-English speaking users. The research noted how the process provided an opportunity to explore bias that can be inherent in human-centred design methodologies and how appropriate advanced consideration of evaluation will help ensure service actors and communities are measuring the same outcome (Bartlett et al., 2021).

The current literature lacks evaluation tools and examples of scaled up initiatives for these groups. However, van den Muijsenbergh et al. (2020), assessing an EU study (RESTORE) involving a participatory methodology to implement training for cross-cultural communications in primary care, found that positive changes in knowledge, skills, and routines in clinical settings with migrant communities were sustained. But a case study from Ireland in the same project demonstrates how structural factors can inhibit positive impacts and stresses the need to leverage greater potential by mapping a network of diverse stakeholders who may have shared goals, but are working in different participatory settings (MacFarlane et al., 2021b). The researchers suggest that involving more senior-level decision makers could improve the mobilisation of resources following pilot projects. De Andrade and Angelova (2020) fill a gap in how to evaluate community engagement for these populations. Working with Black and Minority Ethnic groups and Roma communities, they demonstrate a co-produced methodological evaluation framework – the Asset-Based Indicator Framework (see Figure 3.4) – for measuring the impacts of community involvement on health and inequalities. Phase One identifies existing health assets (beliefs and behaviours); Phase Two identifies conditions/actions for community assets to be activated to engage communities and co-produce services; Phase Three focuses on evaluation and indicators tied to improvement in community environments. Three types of outcomes are identified: quality of life, service process outcomes, and traditional change (e.g., symptoms) outcomes. The researchers highlight that while the research demonstrates the feasibility of co-production, political will and systematic change is necessary for meaningful change to occur. This includes the allocation of resources and capacity in public service organisations, and reconceptualization of evidence, evaluation, and measurement to account for lived experience (De Andrade and Angelova, 2020).

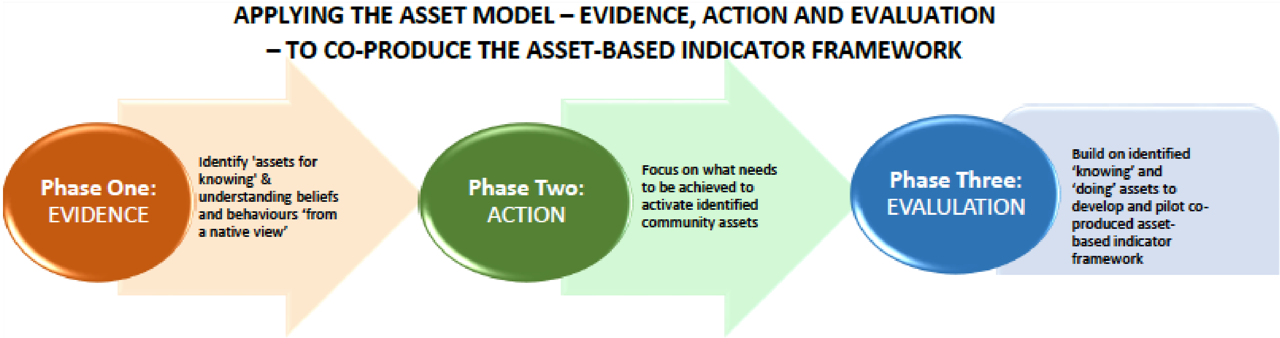

Figure 3.4: Applying the Asset Model to Co-produce the Asset-Based Indicator Framework (De Andrade and Angelova, 2020)

3.7 Traveller Health and Involvement

3.7.1 Forms of involvement

Research on service involvement and the lived experience of members of the Traveller community is primarily dominated by descriptions of community consultations with individuals. This work concentrates on issues of accessible information and services, stigma and stereotyping in health and social care systems, culturally appropriate service provision, and establishing relationships of trust (Van Hout, 2011; Lhussier et al., 2016; McFadden et al., 2018; O'Sullivan et al., 2021). A review of outreach programmes for health improvement found an emphasis on participation, engagement and community empowerment, but with a dominant proportion of descriptive accounts (Lhussuer et al., 2016). This reflects the general lack of attention given to this group within the literature. Evidence of more in-depth involvement initiatives are scarce (McFadden et al., 2018). However, a recent example is seen in the UNITING (UNderstanding uptake of Immunisations in TravellIng aNd Gypsy communities) study, in which, people with lived experience produced recommendations of institutional and policy level interventions for prioritisation (Dyson et al., 2020). The general lack of work on involvement is sometimes connected to the traditional challenges facing this group, and those working with this population. This includes issues around access to and recruitment and retention of participants within involvement programmes, which are linked to this population's 'outsider' status and experiences of discrimination (Condon et al., 2019). It is in this regard that a number of studies note that peer workers have a key role in establishing trust and building bridges within health and social care development (Cafferty and Collins, 2011; Van Hout, 2011; Condon et al., 2022). For example, the contributions of Traveller members of research teams to local community partnership groups have been found to facilitate wider public involvement (Condon et al., 2019; Freitas and Martin, 2015). The low level of coverage in the research literature may also not be an accurate reflection of the extent of the development in the field. For example, in Ireland and as with many other practice interventions across the population groups, it does not capture the work of the Traveller Health Unit (THU). The THU works to advance the health and wellbeing of the Traveller community by working in partnership with the community and providing peer-led supports (HSE, 2017b). Thompson et al. (2022) argue that involving members of the Travelling community in service delivery, as exampled by Traveller Health Units, could improve service suitability, trust and access to information. Other work documents a number of peer-led community-based initiatives to improve Travellers' health outcomes through outreach, health promotion and education (Villani et al., 2021).

Studies with indigenous communities in colonial states such as Canada, the US, Australia and New Zealand presents a similar picture, with a dominance of community engagement strategies and a lack of evidence of deep levels of involvement (Wali et al., 2021; Vincze et al., 2021). However, recent empirical studies indicate a move towards establishing co-production initiatives in Aboriginal health (Bailey et al., 2022). A review of interventions to improve health literacy among Aboriginal and Torres Strait Islander Peoples found inadequate involvement in attempts to address issues impacting the social determinants of Indigenous health, and recommended substantial involvement in all aspects of intervention design and implementation (Nash and Arora, 2021). A review of mental health interventions for Indigenous populations found some evidence of involvement at service level. But the extent of involvement was found to vary significantly, and that wording to describe these strategies varied widely, creating further ambiguities (Lee et al., 2022). The authors note that involvement may sustain positive mental health outcomes, and trained Indigenous persons may integrate acquired skills into services (Lee et al., 2022).

3.7.2 Frameworks and pilot studies

A small number of recent pilot studies demonstrate the potential for service involvement activities involving the Traveller community to become established at an organisational level. For instance, in the context of the COVID-19 pandemic, where members of the Traveller community were considered to be at greater risk of developing COVID-19, response strategies in Ireland included community and partnership-led responses involving community representatives (Villani et al., 2021). The partnerships involved lobbying for resources (e.g., hygiene kits, prioritised testing), and culturally sensitive and literacy friendly information, and were demonstrated to be particularly effective in developing more coordinated and managed on-the-ground responses (Villani et al., 2021). Similar progress has been noted among Indigenous communities in Ontario and Western Australia, where collaborative projects have developed cultural relevant resources and tools (Barker et al., 2021; Wright et al., 2021). In Ontario, a collaboration between a Tungasuvvingat Inuit community and a centre for addiction and mental health aimed to co-create a culturally relevant toolkit of Inuit-specific tobacco cessation resources. An evaluation of the toolkit, implemented through focus groups with Inuit participants, identified how such a process supported: client-centred and responsive care; culturally relevant treatment approaches; capacity-building opportunities; equitable access; and concrete changes to tobacco use (Barker et al., 2021). In Western Australia, sustained relationship building between Elders, service leaders and Aboriginal and non-Aboriginal researchers was found to be critical in co-designed evaluation tools to test the efficacy of a co-designed engagement framework. A three-way survey was developed that records service experiences related to cultural safety from the perspective of those who use services, their carer/s, and the service staff (Wright et al., 2021).

Nevertheless, in general, evidence remains weak. There is a need for evaluations of interventions to improve access to health services, and models of community engagement to identify the best ways to enhance engagement and enable communities to address health issues (McFadden et al., 2018). In an example, Warwick-Booth et al., (2018) in a report on community outreach through partnership between public health team, and a local Traveller-led civil society organisation, use a Theory of Change to develop a framework for programme evaluation. The framework provides for making links between goals, mechanisms for change, context, and outcomes for those who use services as well as outcomes at organisational levels. There is also a need for health services to invest in employing and empowering members of the Traveller community to co-lead a shared approach in organisational decision-making. For example, Crooks et al., (2021) describes the processes and outcomes achieved by a mainstream health service delivery unit developing and implementing a governance model that embedded Aboriginal perspectives. It highlights the importance of commitment and persistence, and acknowledging the challenges arising through cultural differences.

3.8 Shared Barriers and Facilitators

The findings of this review indicated that there are barriers and facilitators of service involvement that are common across the five populations and their engagement in the design, planning, and delivery of health and social care services. It is possible to identify four interconnected sets of factors that influence involvement for the groups: (1) health and life-course considerations; (2) communication, esteem, and engagement issues; (3) organisational and service factors; and (4) major systematic deficiencies. These factors are outlined below, along with some of the specific strategies that have been employed to address such issues.

3.8.1 Health and life-course Considerations

Individual life-course and health factors can serve as potential barriers to involvement. These may include the accumulation of negative health experiences and traumas that have created complex care needs that must be accounted for in practical terms during participation. Research with each of the populations underscore the ways in which such factors can inform a health encounter. For example, for those who have experienced homelessness and who are survivors of gender-based violence, an overarching theme is traumatisation due to previous treatment in service systems and the experience of involvement initiatives (Andrews and Heerde, 2021; Abraczinskas et al., 2021). Barriers may also include factors that stem from cumulative forms of inequality and disadvantage, which have been shown to undermine the trust of individuals in societal institutions and structures, especially in health and social care systems (O’Donnell et al., 2016). Mistrust of services and feeling unwanted or feeling stigmatised have been reported across the populations (O’Donnell et al., 2016; Mc Fadden et al., 2018; Rodriguez et al., 2019; Foster et al., 2021). Studies across these groups have noted that many members of these populations are more likely to have encountered negative exchanges with health services and health professionals (Flanagan and Hancock, 2010; O’Donnell et al., 2016). For example, for those from the Traveller community, a lack of acceptance and understanding of their culture is demonstrated through negative feelings from health service encounters (Van Hout, 2011).

Facilitators to respond to health and life-course factors include recognising the personal and emotional toll of involvement, and implementing practical and psychological supports (Ocloo and Matthews, 2016; Kahan et al., 2020; Mulvale et al., 2019; Andrews and Heerde, 2021; Bell et al., 2021; Ocloo et al., 2021). The provision of a safe and inviting space is noted in research as a means of reducing barriers to involvement. For example, Kahan et al. (2019) found that for women experiencing homelessness, an easily accessible but private location with healthy food and beverage options was a strong attendance incentive. Radl-Karimi et al. (2022), in a study of how immigrant and refugee communities experience the co-production of healthcare services, emphasise the centrality of providing a safe space where health providers listen to and validate their lived realities. In a study on peer engagement barriers and facilitators for people who use drugs, Greer et al. (2019a) found that such practical incentives as food, money and social activities showed respect and value for time and knowledge. Across the five populations, there is evidence in the research that some female participants, such as Traveller women and women experiencing homelessness who are survivors of gender-based violence, are more comfortable in a female-identified group due to having shared experiences (Cafferty et al., 2011; Kahan et al., 2020).

3.8.2 Communication, esteem and engagement issues

Communication and esteem challenges pose obstacles in the face of an emphasis on verbal, writing, and other social skills in healthcare encounters (Beresford, 2020; Ocloo et al., 2021). For example, McFadden et al. (2018) reports a key set of barriers for Roma and Traveller communities to be literacy, language, and health literacy. The words and phrases used in health and social care are highlighted as being easily misinterpreted (O'Donnell et al., 2016). Additionally, where healthcare systems rely on information communication technology, this can present a further barrier (Palumbo, 2016). There is also often a significant social distance between health providers and people who experience marginalisation observed in research across the populations included in this study (O'Donnell et al., 2016). As such, discrimination and prejudice has been found to arise in healthcare encounters where individuals are seen as problematic or disruptive due to their circumstances or background (Beresford, 2020).

In order to address communication, esteem, and engagement issues, central facilitators include: building confidence and skills, advocacy, and peer support (De Freitas and Martin, 2015; Ocloo and Matthews, 2016; Luchenski et al., 2017; Mulvale et al., 2019). Chauhan et al. (2021a), in a study on optimising co-design with people from ethnic minority communities, found that working though peer-led community groups to approach individuals about involvement leveraged existing relationships of trust, thereby identifying their needs, and addressing their concerns in an appropriate way. In a study by Ryan et al. (2017), people from a migrant background and those who use drugs reported being guided through conversations as important, while members of the Travelling community considered signposting to further support as important. Respect for confidentiality and clear communication were also found to be key considerations across studies on these populations (Ryan et al., 2017). Radl-Karimi et al. (2020), in a scoping review about facilitators for co-production with immigrant populations, note the importance of avoiding the use of jargon, using understandable language, providing visual materials, and attending to non-verbal communication. The display of art work that is representative of the cultures of different minority communities has been shown to promote the levels of comfort experienced by those who use services (Cafferty and Collins, 2011). Larsen et al., (2022), reporting on co-produced research on enhancing involvement in mental health, recommend the co-development of a mutual agreement around how to address issues of power, exclusion/inclusion, and expectations of confidentiality, trust and decision-making.

3.8.3 Organisational and service factors

There is an extensive body of literature that attests to the disruptive influence of barriers arising from organisation and programme level factors. Many of these can reflect broader macro and systemic issues, but may also directly stem from the structures and cultures of individual organisations (Larsen and Sagvaag, 2018; Larsen et al., 2022). These factors include a lack of clarity regarding the role of service involvement within an organisation, or the individual roles of actors. They can also include practical barriers caused by operating structures and bureaucracy within organisations. For instance, the structure of primary care services – connected with the nature of an opt-in system for public healthcare – makes it difficult for populations who experience marginalisation to engage with these resources (O'Donnell et al., 2016). Physical factors such as the location of and transport to service centres can present further barriers (Flanagan and Hancock, 2010). Challenges also include a lack of commitment to services and/or a deficient allocation of funding or other critical resources on the part of the organisation to service involvement strategies (Phillips and Kuyini, 2018). Burgess and Choudary (2021), in a study of the co-production of mental health services for populations who experience marginalisation, stress that responses to 'what matters to you' can include the desire for change beyond what is perceived as the remit within the health system.

A common organisational barrier to meaningful involvement reported in the literature is also the negative attitudes of some staff, leading them to resist, sometimes actively, service involvement (Boaz et al., 2014). One reason for this is how knowledge is hierarchically conceptualised, with that of health care professionals valued as 'expert', while the experiential knowledge of those who have lived certain experiences or conditions is seen as weaker (Tambuyzer et al., 2014). Preconceived negative assumptions or stigmatised attitudes towards those with lived experience, especially those who are likely to be marginalised in everyday life, can fuel perceptions of these people as not 'right thinking'. The relationship between attitudes and involvement is circular – Patterson et al. (2010) observe any failings of people who use drugs were considered to reinforce a stereotype that they did not have the capacity for effective involvement, rather than pointing to organisational issues such as a lack of infrastructure and support. Nonetheless, efforts to transgress discourses of hierarchical expertise, for example by valorising lived experience knowledge over professional knowledge, Moore and Zeeman (2023) argue, often result in powerful resistance. This is because it would represent a significant change, and one which may threaten the social and professional values, norms, and codes of these actors (Boaz et al., 2014). While this may relate to fears of criticism arising out of service involvement processes (Omeni et al., 2014), it is more likely to that resistance to service involvement is driven by fears around its potential to alter power relationships (Moore and Zeeman, 2023; Phillips and Kuyini, 2018; Ocloo and Matthews, 2016; Boaz et al., 2014; Tambuyzer et al., 2014).

Improving involvement can require systematic responses to address organisational barriers. Research has found that directing time and money to involvement in services is not enough without complementary initiatives, such as staff training (Phillips and Kuyini, 2018). Cultural responsiveness training, and working in partnership with support agencies for minority ethnic communities, are cited as being effective for increasing cultural awareness and meeting the needs of people from ethnic minority communities (Cafferty and Collins, 2011). Informing people who use services about involvement initiatives is also an important step to overcome service level barriers (Phillips and Kuyini, 2018). For instance, Ferguson et al. (2011), found that many participants in a study involving youth who experience homelessness were unaware that they could provide an opinion or feedback on services. Outreach services, coordinated across services and incorporating peer involvement in design, is recommended in Traveller health (Cafferty and Collins, 2011). Practical facilitators include transport to services, flexible opening hours and outreach services (Flanagan and Hancock, 2010; O'Donnell et al., 2016). For example, Kahan et al. (2020) addressed barriers with people experiencing homelessness through public transport tokens, evening scheduling, flexible staff availability, and phone availability of the group coordinator. In a study on the use of technology in co-production, Bakkeli and Grønningsæter (2020) found that technological solutions can play an important facilitating factor in involvement by strengthening access to services and supports.

3.8.4 Major systematic deficiencies

Ingrained cultural mindsets embedded within traditional hierarchies and power structures in health and social care systems, can prevent the prioritisation of service involvement, in particular for groups who experience marginalisation (Beresford, 2019; Madden et al., 2020; Ocloo et al., 2021). Regular health care providers and those who use services may have different understandings of what matters in health care provision – a situation that can become more problematic in complex and challenging health care contexts (Palumbo, 2016). These factors inform an operational environment where neither a meaningful ethos of involvement can develop, nor where the value of input from those with lived experience could be recognised or harnessed. Such barriers place practical limits on the implementation of scalable and sustainable service involvement initiatives that would target specific populations. More broadly, systematic challenges such as economic and social circumstances, for instance precarious housing or employment, can also fundamentally impede any form of meaningful involvement (O'Donnell et al., 2016; Mulvale et al., 2019). Villani et al. (2021) observe that Traveller and Roma marginalisation can, amongst other issues, be attributed to lack of economic and political power. Connectedly, not paying participants can deter people with limited resources from becoming involved (Ocloo and Matthews, 2016). People who use lived experience to inform their work as peers in employment settings also face barriers to payment, such as bureaucratic financial services (Greer et al., 2019b).

Palumbo and Manesh (2021) assert that it is essential to attend to dismantling power dynamics that privilege regular healthcare producers. Equal power distribution can be facilitated through, for example, developing terms of reference (Chauhan et al., 2021a). Allyship has been found to be a significant support for the growth of involvement (Gordon et al., 2021). In the context of mental health, Gordon et al. (2021) call for members of more privileged groups to support the goals of groups who experience marginalisation by engaging in processes that address imbalances of power. In this regard, Palumbo and Manesh (2021) suggest that decentralisation is fundamental to overcome barriers to systematic involvement, allowing for greater adaptation of co-production models to the needs perceived by groups who experience marginalisation. Third sector organisations have also been noted to play a key role as intermediaries, promoting co-production and absorbing the complexity of involvement arrangements, and accordingly require support (Palumbo and Manesh, 2021). Beresford (2019), argues that an essential first step to advancing involvement in health and social care is to place it in the context of developing democracy. Beresford identifies four key overlapping stages in this process: working for representative democracy in the achievement of universal suffrage and social rights, including the right to health; provision for participatory democracy and community development; provisions for involvement in health and social care; and, as needed, State reaction, and renewal or redirection led by those who use services.

3.9 Population Specific Barriers and Facilitators

In addition to the common barriers and facilitators applicable to all of the five populations, there are also factors specific to each group that need to be accounted for in supporting service involvement for these groups. Some of these factors are linked to the common barriers outlined above, but reflect particular nuances in experiences related to the distinct profiles and circumstances of these groups. In other cases, they go beyond those factors listed thus far. A brief summary of these barriers and facilitators are now presented.

3.9.1 People who use drugs and alcohol

For people who use drugs and alcohol, a primary barrier is a traditional hierarchical division of power and knowledge. This division often stems from perceptions of deficits and unreliability attributed to those who use services (Treloar et al., 2011; Rance and Treloar, 2015; Goodhew et al., 2018; Wenaas et al., 2021a). Mutual distrust is another significant barrier, which may result from professionals' fear of deception and stigmatised perceptions on both sides (Park, 2020b; Jones et al., 2021; Wenaas et al., 2021b). The presence of individuals still using drugs and alcohol can also complicate involvement (Goodhew et al., 2018; Jones et al., 2021). Physical health barriers, such as the effects of drugs and symptoms of withdrawal, contribute to these challenges, particularly when coupled with the experience of stress before and during treatment (O'Donnell et al., 2016; Wenaas et al., 2021b). The fear of being judged, pathologised, or fear of exposure, can further deter involvement (Greer et al., 2019a; Almeida et al., 2020; Bakkeli et al., 2020; Park et al., 2020a; Selseng et al., 2021). Additionally, doubts regarding the capacity of those who use services and the sustainability of their involvement, can lead to reluctance to involve them, particularly in higher-level activities (Patterson, Weaver and Crawford, 2010). Whereas concerns about potential relapse or endangering the recovery of those who are abstinent may also heighten apprehensiveness to engage with some of these groups (Goodhew et al., 2018; Greer et al., 2019a).

Facilitators of service involvement for people who use drugs and alcohol can include the employment of people with lived experience to advocate for peers and promote trusting relationships, as they are likely to be well informed and understanding. The benefits of developing relationships with peers have as such been particularly noted (Bakkeli et al., 2020; Jones et al., 2021). The inclusion of peer networks for supporting participation (Greer et al., 2016; Greer et al., 2019a; Park 2020b), the support of family (Wenaas et al., 2021b), and mutual and periodic feedback on progress and outcomes (Park, 2020b; Jones et al., 2021) have all been found to create a more enabling engagement environment for members of these groups. In terms of more culture change values, a non-judgemental approach with a more equalised relationship between staff and those who use services has been found to facilitate engagement (Selseng et al., 2021). Likewise, supportive attitudes, raised awareness of collaboration skills, and mutual respect are fundamental to facilitate involvement for this population (Goodhew et al., 2018; Wenaas et al., 2021a).

3.9.2 People who experience homelessness

For those who experience homelessness, there are a number of individual level considerations that reflect the precarious environmental living conditions of these groups. Primarily, the transient nature of homelessness means that ongoing engagement to achieve meaningful involvement over a period of time can be challenging (Mullins et al., 2020). For instance, O'Donnell et al., (2016) and Clifford et al., (2022) found that there may be more immediate needs to meet, such as food and shelter, or that regularly changing location may impede use of services, not to mention involvement (O'Donnell et al., 2016; Clifford, 2022). Furthermore, additional barriers can be present as a result of complex healthcare needs that require referral between systems, and the absence of the means to access service locations (Clifford et al., 2022; Currie et al., 2022). Additionally, Andrews and Heerd (2021) note that housing instability can cause difficulty in producing documentation, such as related to employment or qualifications.

One significant facilitator to counteract some of the more material barriers includes appropriate reimbursement and a range of payment options to help not just encourage but support engagement (Foster et al., 2021). Phillips and Kuyini (2018) recommend that services should at the very least implement the 'informing' component of the involvement process as a first step due to the possible short-term nature of service delivery and the transience of many sections of the population. Mullins (2021) and Barker (2017) found that a key facilitator was a peer worker with lived experience and street knowledge. Key enabling strategies also include outreach and coordination across shelters and partner agencies

(Abraczinskas et al., 2021; Kahan, 2020). Especially within a shelter setting, a sense of physical and emotional safety in the involvement environment is paramount (Abraczinskas et al., 2021; Kahan, 2020).

3.9.3 People who use mental health services

People who use mental health services can experience barriers involving the impacts of mental health and emotional implications of bringing lived experience into involvement activities (Faulkner and Thompson, 2023). Perceptions of those who use services as vulnerable and needing to be protected, or as not interested or able to engage, also form barriers (Kennedy et al., 2017; Kirwan, 2020). These perceptions contribute to the dominance of a traditional medical model and embed professional power dynamics in mental health care (Gordon et al., 2021; Mirbahaeddin and Chreim, 2022). The presence of such beliefs demonstrates the extent of stigmatisation that can impact those who use mental health services (Stomski and Morrison, 2021). A key challenge is, therefore, to overcome the privileging of the knowledge of health professionals over the knowledge gained through lived experience (Gordon et al., 2021; Larsen et al., 2022). Burgess and Choudary (2021) observe that for those who use mental health services in particular, involvement can be embedded within a history of violence, with particular implications for those from historically marginalised groups.

Traditional facilitators of engagement for this population are diverse. They include information and learning programmes that are co-produced to incorporate recovery perspectives, acknowledging the value of self-experience as well as formal learning (Higgins et al., 2020). They also include establishing a representative group of people with lived experience to support those who use services in their right to exert influence (Dermody et al., 2015; Mirbahaeddin and Chreim, 2022). In this manner, involvement must avoid the pitfalls of the past by attending to historical oppression, and social and power inequalities (Burgess and Choudary, 2021; Pound and Sims-Schoutenet, 2022), with a need to rethink traditionally privileged positions considered to be a key step (Gordon et al., 2021). Therefore, it is often argued that it is necessary to focus on more than just individual treatment outcomes with a view to reducing mental health inequalities faced by groups who experience marginalisation. A facilitator identified to support involvement in mental health services that could be applied across the target populations is the ‘phase zero’ approach (Burgess and Choudary, 2021). ‘Phase zero’ refers to developing relationships, collaborative projects and service engagement before ‘official’ co-production activities. It shifts power, resources and relationships through recognising and addressing inequalities and historical barriers. This involves creating spaces for support and dialogue about emotions between participants (Faulkner and Thompson, 2021; Larsen et al., 2022) and providing support to engage optimally, including that of peers (Kennedy et al., 2017). Allyship and the involvement of advocacy groups has been found to be important to support the cultural shift necessary to help counter any power imbalances that may be ingrained within mental health care service (Gordon et al., 2021; Stomski and Morrison, 2021). Additionally, it is crucial to deliver interventions that reduce the stigmatisation of those who use services through education, professional development and communication (Stomski and Morrison, 2021; Larsen et al., 2022).

3.9.4 Migrant, minority ethnic and Roma communities

The involvement of migrant, minority ethnic, and Roma populations in services faces several barriers. These include language barriers, immigration status, and discrimination (Chauhan et al., 2018; Condon et al., 2019; Dyson, 2020; Kellezi et al., 2021; Røhnebæk and Bjerck, 2021). These populations may also be faced with poor mental health, arising from traumatic experiences and the stress associated with displacement (Radl-Karimi et al., 2020; Kellezi et al., 2021). Furthermore, mistrust and fear of harm often present significant barriers to involvement (Condon et al., 2019). Cultural beliefs pertaining to sensitive health topics or gender-specific issues can only serve to complicate these dynamics (Condon et al., 2019; Mc Fadden 2018) and hinder effective communication and understanding (Dawson et al., 2017; Mc Fadden, 2018). De Freitas et al. (2020) found that communication issues were more commonly reported by migrant and ethnic minority women. There is often inadequate support for these communication challenges, including a lack of interpretation services (Harrison et al., 2020; MacFarlane, et al., 2021a). Moreover, individuals who are undocumented or seeking protection may not feel safe when interacting with health services, further exacerbating these barriers to involvement (MacFarlane et al., 2021a).

Due to cultural considerations such as different healthcare assumptions and expectations, strategies to promote involvement should address communities directly. This can incorporate encouraging small groups to interconnect, informing group representatives of institutional participatory mechanisms; assess their views of involvement, and work with them to discuss their goals; and consider the necessary resources and logistical supports (including language, cultural, and religious considerations) (De Freitas et al., 2014; Chauhan et al., 2021a; Kellenzi et al., 2021). Chauhan et al. (2021a) recommend language support, financial support and access support, additional time to process and respond to tasks, and consideration of cultural and religious calendars and traditions. Cultural sensitivity, including the influence of culture on values, beliefs, and attitudes is an important prerequisite, as is the promotion of cultural competence in the system at staff and organisational levels through training incorporated into health policy, and safety and quality frameworks, as well as diversity and cultural competence training (Chauhan et al., 2018; Mc Fadden, 2018; Harrison et al., 2019; De Freitas, 2020). The implementation of explicit national policies for migrant involvement can also facilitate engagement (MacFarlane et al., 2021a).

3.9.5 Members of the Traveller community

Traveller communities often face unique barriers in accessing and engaging with health services. These barriers can stem from cultural differences, bureaucracy, geographical distance to services, health literacy gaps, and a pervasive fear or mistrust of services due to previous experiences of discrimination (McFadden et al., 2018; Condon et al., 2019). The living conditions prevalent within these communities, often characterised by sub-standard accommodation, can pose further obstacles to enhanced service engagement (O'Donnell et al., 2016). The challenges of maintaining the Traveller traditional way of life alongside housing restrictions can lead to isolation, dislocation, and an absence of social security, causing further barriers for people to negotiate (Van Hout, 2011). There also exists practical limitations, such as the absence of a fixed postal address for the delivery of appointment cards, shared mobile phone numbers, and the complexity of tracking health records for mobile individuals (Van Hout, 2011). Furthermore, fear of disclosing ethnic identity due to previous negative experiences, coupled with concerns about compromised confidentiality, contribute to the barriers faced by this group (Cafferty and Collins, 2011; Van Hout, 2011).

Facilitators of involvement for members of the Traveller population can include: a respectful approach; the involvement of community members in specialist roles; outreach and dedicated services; raising health awareness; handheld records; and cultural awareness

(McFadden et al., 2018; Condon et al., 2019). Specifically, Van Hout (2011) finds that Travellers refer to a focus on peer training to disseminate educational material as an important facilitator, to circumnavigate barriers such as literacy issues and inadequate outreach efforts. Travellers also emphasised the need for consideration of gender in peer-led educational models due to gender-based differences in health issues such as substance use (Van Hout, 2011). Warwick et al. (2018) observe that men may be less willing to discuss health, while Traveller women may not feel comfortable attending health care alone. This has implications for both how men and women are included in services, and may require the involvement of friend or family groups, and the need to match the gender of the person they engage with (Cafferty and Collins, 2011). The need for services to utilise ethnic identification systems to track trends in access, participation and outcomes, and guide service responses and developments, has also been highlighted as a means to enable an environment where individuals feel safe disclosing their ethnicity (Dyson et al., 2020).

3.10 Key Messages

1. According to existing research, the importance of service involvement is generally recognised across health and social care settings for the five populations, but the nature and degree of involvement differ notably across these populations.
2. People who use mental health services and people who use drugs and alcohol receive significant attention in service involvement research, while homeless, Traveller, and migrant, ethnic, and Roma populations receive comparatively less focus, with an emphasis primarily remaining on individual decision-making and community-based initiatives.
3. The mental health field demonstrates the most advanced involvement, using established frameworks and tools to incorporate individuals' preferences into care planning and co-production of services. Further work is necessary to measure and monitor the effectiveness of these practices.
4. Involving those who use services in the co-design of digital tools, especially within mental health care, is a growing trend, showing promise despite challenges around integration within the wider health and social care information technology system.
5. Each sector has specific challenges and areas for future development, including the need for more effective involvement strategies, evaluation tools and methodologies, and methods to ensure that involvement leads to improved outcomes.
6. There is a pressing need for further research and involvement, aiming to balance representation in service involvement programmes and address the unique challenges and considerations of each group.

Peer Research Case Study 2 - Access to homelessness support and drug use services

By Joseph Griffin and Jayde Byrne

Jayde and Joseph discuss how meaningful, holistic support services for homelessness and/or drug use need to be made easier to access. In particular, they highlight how the whole person needs to be involved in the process of delivering appropriate services, allowing for individuality.

Engaging with the whole person - *Joseph (with editorial support from ICSG researchers)*

This photo illustrates the start of a journey in which Joseph experienced no trust in anyone. Feeling alone, this particular ash tree in a Dublin park grounds him and has become his roots.

I've slept under this tree since I was 13. It's an Ash tree and it's really old. When I looked at the tree I thought 'you're fecked up like me'. The tree was me pal. If you walk around the tree you'll see devils, angels, monsters, Neanderthals, and the more you're off your face the more images you see. I'd just fall asleep on my own under the tree. The park rangers don't bother me. I'm never afraid there, sleeping alone outside is easy. The tree is a comfort to me, it's always there, but it hasn't got too long left. They clipped her back for health and safety reasons and there's feck all left on her. I'd say another winter and she'll be gone. I wouldn't get attached to another tree though.

I'm all my life meeting people, who get paid to care for me, telling lies. All the bars on windows I have been behind, and doors slammed in my face. All the locks I tried to open – the only key that ever worked was my Key Worker with 'Merchant's Quay Ireland (MQI)'. [He] is a good man, and I bounce problems off him, without him banging on and on about religion or nothing. He's been through the wars. I like him – he's a safe pair of hands. I get medication from him to think normally. Most of my life I've been psychotic, I *can't tell the difference between reality and pharmacy. These meds keep me as normal as possible. I have the most boring life but for the first time in me life I actually like it.*

Listen to the whole me – *Jayde (with editorial support from ICSG researchers)*

Jayde chose not to present photos, describing instead her personal experiences with service providers in the areas of drug use and homelessness.

Service providers need to help people to progress with their lives – not just give folk medication. I was never asked would I like to see anyone to talk about why I used drugs to get through life. All the doctors done was give me Methadone and other meds for years. I had tried to stop many times, but I couldn't, and I'd find myself back where I started from every time. So I began to feel that was all life had to offer, and I just accepted that was my life. I went from clinics to doctors being given different drugs each time for many years. Nothing changed till I found a day programme called 'Soilse'. I went there with no reason to want to go on in life. In this programme they listened to me and to what I felt I needed to improve my life. They helped show me I didn't need a substance to get through the day. They guided me to NA (Narcotics Anonymous) and CA (Cocaine Anonymous). The counsellors there asked how we were getting on in life and sent us for treatment. It was a safe place to talk about why I used drugs. These people gave me my life back.

I am drug-free today and happy in life again. I graduated from this programme after ten months of the best days of my life I had in years. I met some of the best, caring people I have ever known. I have my own home today. The Peter McVerry Trust stood by me and got me out of hostels and into a house. I can put my head down at night happy to live again. The handful of caring people in Soilse trusted me and saved my life. I'll always be grateful to them for their compassion, respect and love. They believed in me.

Conclusion – Joseph and Jayde

*I **(Joseph)** like to be left alone. I don't do lonely. I live outdoors some of the time. It's not a hardship. I live by the rivers, canals, fields – as long as I'm not around people. I just use Merchants Quay Ireland for a shower and to eat and get meds and then get out. I don't need more than that. We're not all the same. There are others like me too. We don't all want to go into Rehab and go to colouring classes.*

*I **(Jayde)** just want service providers to give people like me what I need and actually want. We both want service providers to really listen to what we have to say so we can tell them what we need and why we need it. Take the time to find out about our backgrounds and why we're asking for help. They can deliver better services if they listen to what we actually need.*

4. Current State of Service Involvement for the Five Populations

This chapter presents research findings on the current state of service involvement among the five population groups in Ireland. The findings are organised by each set of study informants. The perspective of national stakeholders (based on interview data) will be first presented. This is followed by the perspective of service providers (based on focus group and survey data). Finally, the perspectives of the lived experience participants from the five populations (based on focus groups and interviews) are presented.

4.1 National-Level Stakeholder Perspective

National stakeholder interviewees were broadly positive about the potential of service involvement and more specifically, public and patient engagement within the health and social care sector in Ireland. However, generally there was a sense that this potential had yet to be realised with many interviewees describing very real limitations on progress. Stakeholders' perceptions of positive developments regarding service involvement are first described, with the constraints on progress then outlined.

Most of the interviewees noted that service involvement had advanced in recent years with levels of awareness and practice growing – albeit from a low base. All nine interviewees were able to describe at least one positive example of an initiative that is currently being, or has recently been, undertaken. Many of these examples were located in the general health and social care sector, and outside of the specific population groups. Nevertheless, several stakeholders did suggest that engagement activities were more established within some of the projects and supports for the Traveller community and, as this quote illustrates, within mental health services:

> *Mental health...did a lot of work on… trying to bring back people who'd had a mental health experience, you know, and bringing them back to teach others. They've done a huge amount of work around that, which was fantastic.* (IN.SH.03)

A number of participants also highlighted the period of the COVID 19 pandemic as being a catalyst for promoting awareness of different forms of lived experience participation:

> *…having spaces where we can champion the different models of service user participation [is important]. I think COVID again…. has definitely there is no doubt, but it's definitely increased the recognition of the value of listening to service users. And so, that is becoming more evident around you know, new policies or new developments…* (IN.SH.09)

Interviewees pointed to developments at a national level that were beginning to pave the way for service involvement in general, describing guidance documents (for example National Standards for Better Safer Healthcare) and structures (for example, the Your Service, Your Say programme) in place for service involvement. A range of initiatives and processes that were considered to be beneficial in advancing involvement were also described. This included the wider prevalence of lived experience perspectives on service evaluation committees, patient councils, expert panels, and strategy development teams:

> *… there would have been patient reps on all the recent [national health and social care] strategies…I think their experience has been good, very good overall.* (IN.SH.07)

It also included the roll-out of large-scale national information gathering initiatives that were viewed as establishing the voice of people with lived experience as a driver of service improvement, as this stakeholder with a remit for service-user feedback describes:

> *… there's been an annual patient experience survey since 2017 and I go through the comments every year to see if there's anything new there….So, wherever the survey programme goes, we will look at the feedback and tailor our (staff training) programme accordingly…Our programme is entirely based on what patients are telling us. And we did add some extra modules and skills training into the programme following the [feedback].* (IN.SH.01)

Interviewees also cited certain approaches as being particularly important in fostering service involvement in Ireland, such as co-production, the involvement of peer-workers, and, although not widespread more generally outside the work of representative organisations, capacity building efforts. As noted by this interviewee in relation to (service development/policy development), these approaches can help to embed more of a partnership approach to service delivery.

> *…what we have learned is that people who work with us, they don't see themselves as patient representatives, they see themselves as more like patient partners because of the nature of their involvement…*(IN.SH.05)

Critically, however, most interviewees conceded that the rate of progress with respect to service involvement is slow. People felt that large-scale benefits had yet to be achieved, and that activities were not sufficiently coordinated within the health and social care environment. Interviewees also noted that these gaps were often most evident with respect to the five populations groups. This is illustrated by the following quote from a national stakeholder who feels there is a dearth of meaningful service involvement for these groups:

> *First of all, they're not included. They would have a lot of people advocating on their behalf. Different groups, you know… I think mental health, I think there's not enough services for patients and I think they are a forgotten group sometimes, but they're one group. But I think the homeless, I think Traveller community, Roma in particular, I would say they're not from my experience anyway represented at all.* (IN.SH.03)

A number of participants felt that service involvement or public and patient engagement had yet to penetrate and truly impact the policy process. For some working within policy development, it was clear that these sorts of considerations and activities had yet to feature within their work:

> *I know very little about it [service involvement]. I think it is something that colleagues […] have been doing some work on. But it hasn't really filtered down to me, the whole issue of public patient engagement. It's not something that's discussed […], I haven't really come across this.* (IN.SH.04)

For national stakeholders who had been involved with and had attempted to embed service involvement within policy and practice over an extended period, there was a clear sense of frustration that more progress had not be made. Even with some of the advancements, many stakeholders pointed to the significant changes that they felt were still needed to establish service involvement within health and social care policy and practice, and particularly for the five population groups. A participant who had a high-level role in the HSE describes how the complexity of the health and social care sector and the speed at which actions emerge as priorities, is not always conducive to meaningful engagement under the current system:

> *You know, particularly the last couple of years, a lot of what we do… like, a lot of our priorities are things that become urgent very quickly. And we set things up to implement things and all the rest. So, I think it takes time to identify people to engage. Sometimes we have to set up a group like that and get something moving. And actually, getting the service user engagement bit of it right takes a bit of time. So, I think that our system is so big and busy and complex, it doesn't always lend itself to readily engaging.* (IN.SH.06)

Many stakeholders also noted that tokenistic service involvement can be all too common. In these instances, service involvement was seen as a 'tick box' exercise, where lived experienced participants are brought in later in the process, once services have already been developed. For some, the developments were impeded by more fundamental challenges related to actual action with, as this stakeholder concisely illustrates, a number of participants concerned about implementation and follow-through to ensure impact and meaningful sector transformation:

> [Service involvement is]… *in its infancy I would say, and there's a long way to go…I suppose in Ireland we're better at setting policies than implementing them.* (IN.SH.2)

4.2 Service Provider Perspective

With respect to the current state of service involvement for the five populations, there was broad consistency between the themes evident within the focus group discussions, and the results of the service provider survey. There was generally consensus amongst focus group participants that there was moderate level of service involvement happening with all five groups in Ireland. As with national stakeholders, it was relative improvements in the level of engagement that were typically noted for each group, with differences across populations observed in providers' descriptions of the nature of involvement. Focus group participants highlighted that in overall terms there was a greater intensity of engagement activity in mental health services, with some specific successes reported by those working within these services. In contrast, providers within the areas of homelessness, drugs and alcohol, and migrant, minority ethnic and Roma groups were more likely to note how service involvement had become more prominent, but continued to lack a real embeddedness within services.

With reference to Figure 4.1, survey results indicated an even healthier level of activity, with 93 per cent of the 320 respondents reporting that their organisations engaged in service involvement of some form. This very strong rate of engagement was consistent across organisations working with all participant population groups, and across all organisation types (i.e. NGOs, Sections 38 and 39 organisations, hospitals or other health institutions, other public sector organisations, social enterprises), with 49 per cent of respondents stating that their organisations had been engaged in involvement activities for 10 years or more. Unless stated otherwise, all other survey findings that will be presented in this report are based on those organisations engaging in service involvement (i.e. 93 per cent of the total sample).

The results of the survey also suggested some positive aspects regarding the nature of these engagement activities. Sixty-eight per cent of respondents reported that service involvement with those who use their services was on an 'on-going' basis, with only 4 per cent of respondents indicating that they engaged 'less than annually'. However, there was a large variance among the groups with 80 per cent of those from the mental health sector reporting 'ongoing' service involvement, 75 per cent of the Traveller provider respondents, 68 per cent each in the homeless, and drug and alcohol sectors, and just 35 per cent of those providing services to migrants, minority ethnic and Roma people. Furthermore, just under half of respondents (47%) reported that they engaged in involvement activities that comprised of 'sustained and continuous engagement with the same stakeholders'. Just over a third (34%) reported that their involvement activities included 'repeated engagements over a fixed period', and just under a quarter of respondents (24 %) stated that their service involvement included 'once-off engagements'. Together these findings suggest respondents were more likely to be engaged in involvement activities of a more sustained or repeated form.

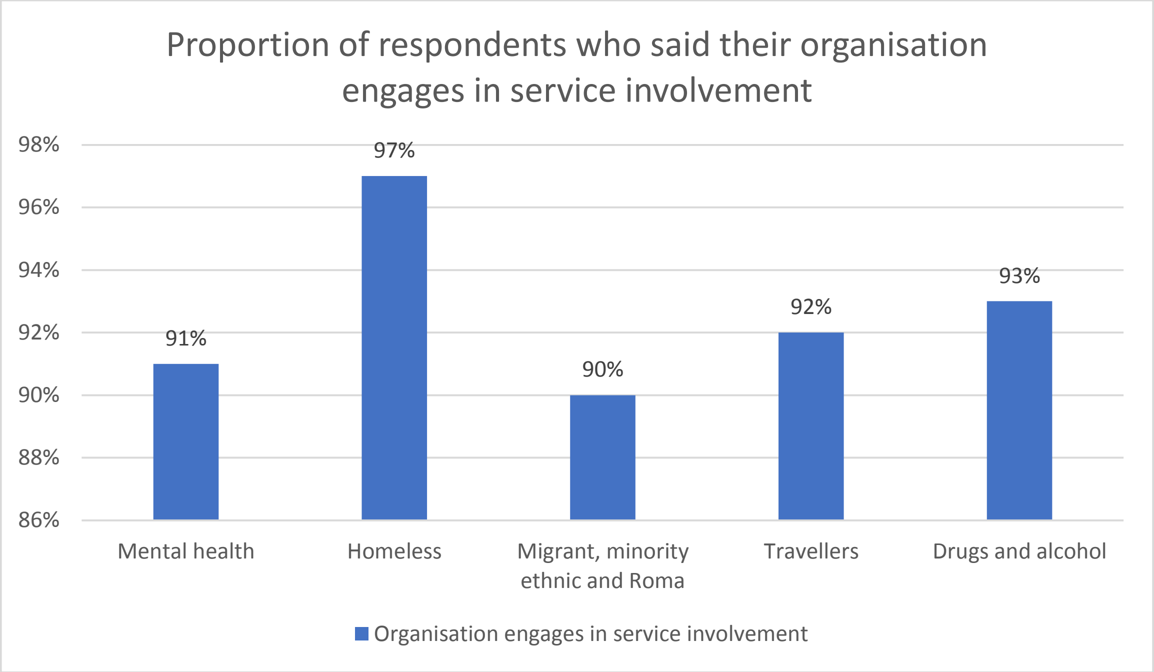

Figure 4.1: Levels of service involvement by population stream

However, notwithstanding the significant levels of engagement and the robustness of these survey patterns across groups, it was clear that high-quality engagement was not guaranteed. Issues related to the quality of engagement activities were, to some extent, albeit to different degrees, identified within all focus group discussions for all groups.

First, many service providers across the groups reported how current service involvement generally lacked standardization for the populations. Participants spoke about the inconsistency in the terminology used to describe service involvement – such as consultation, engagement, service-user involvement and PPI – and in how different involvement strategies were implemented. As a result of these inconsistencies, it was felt that there was an absence of a shared understanding and approach within the health and social care sector, and a general confusion regarding what involvement should mean and what it should entail. Survey respondents generally supported this finding, with 53 per cent reporting that lack of clarity around service involvement was problematic in engagement activities. A service-provider focus group participant succinctly sums up this challenge:

> *... one of the things that we've really been grappling with…is like, what is it we're talking about…some of the people around the table…they meant different things by [service involvement]...* (FG.SP.HO)

Despite some of the advances in establishing involvement activities in mental health services, providers working in this area also raised these concerns. As this participant highlights, while progress had been made in developing some form of common understanding, inconsistencies could remain even within the same service region:

> *Listen, I absolutely agree there's been, there's a huge improvement kind of in the last decade with regards to a shared understanding I suppose of what engagement means… But now the challenge is about rolling that out I suppose on a consistent basis so that there is consistent understanding of what that looks like for service users and their families, you know. I suppose a big challenge I see and I've only recently kind of come to [specific CHO area], so I can see it in terms of our catchment area spreads all the way from [town in north, to town further south], is the differences between how teams engage with service users, with families, how they would interpret recovery, engagement, the importance they would place on that.* (FG.SP.MH)

Second, focus group and survey findings also pointed to questions regarding the depth of current engagement activities. Although participants and respondents highlighted that there was an openness amongst their organisations to engage (which 69 per cent of survey respondents had reported), it was noted that this openness did not always translate into high quality engagement. Within focus group discussions, more involved partnership or co-production approaches were described for some service areas, for example in relation to mental health services, for Travellers, or in relation to recovery education for those using drugs and alcohol services. But many participants argued that engagement was less involved. These providers felt that efforts were all too often superficial, where people with lived experience were not really listened to, or sufficiently supported to contribute in a meaningful way. In such cases, engagement was deemed to be involvement in name only with those with lived experience having little impact on decision-making. This was the sentiment of one Traveller service provider speaking about the involvement of members of the Traveller community in service development:

> *[Service involvement should not be] seen as 'we just need one or two of them sitting in the room and then we're all covered and we can go ahead and do what we like, and we can say we've had Travellers involved'* (FG.SP.TR)

As a result many focus group participants across all population groups felt that some service involvement activities were tokenistic and not meaningful enough. As illustrated by this quote from a mental health service-provider, there was a distinction for some participants between simply just doing involvement and making involvement 'real':

> *So, I think there's something about you know, this being valued at all levels within the organisation and not just 'oh we have X person on the committee, so therefore we're doing this right'. That doesn't really mean anything…it has to be real.* (FG.SP.MH)

The observations of focus group participants were generally supported by the results of the survey, and the provider responses to the 'Ladder of Participation' survey item (New Economics Foundation, 1999). With reference to Figure 4.2, respondents were more likely to report that involvement activities took place at the less involved levels of 'engaging' (individuals can express views and influence some decisions), 'consulting' (individuals invited to provide views in surveys/at meetings) or 'informing' (telling individuals about a service). Whereas respondents were less likely to report involvement at the 'co-design' (individuals can influence some decisions) or 'co-producing' level (individuals involved in all decisions from design to delivery). However, some variability in responses across the population groups was evident. Mental health service providers were almost as likely to report involvement at the level of 'co-production' (60%) as at the 'engaging' (64%) level. Rates of 'co-production' were much lower for the drug and alcohol service providers (23%), the homeless service providers (15%), and the migrant, minority ethnic and Roma service providers (12%). In addition, an equal proportion of those providing services to migrant and minority ethnic populations selected 'engaging' and 'informing' (71%).

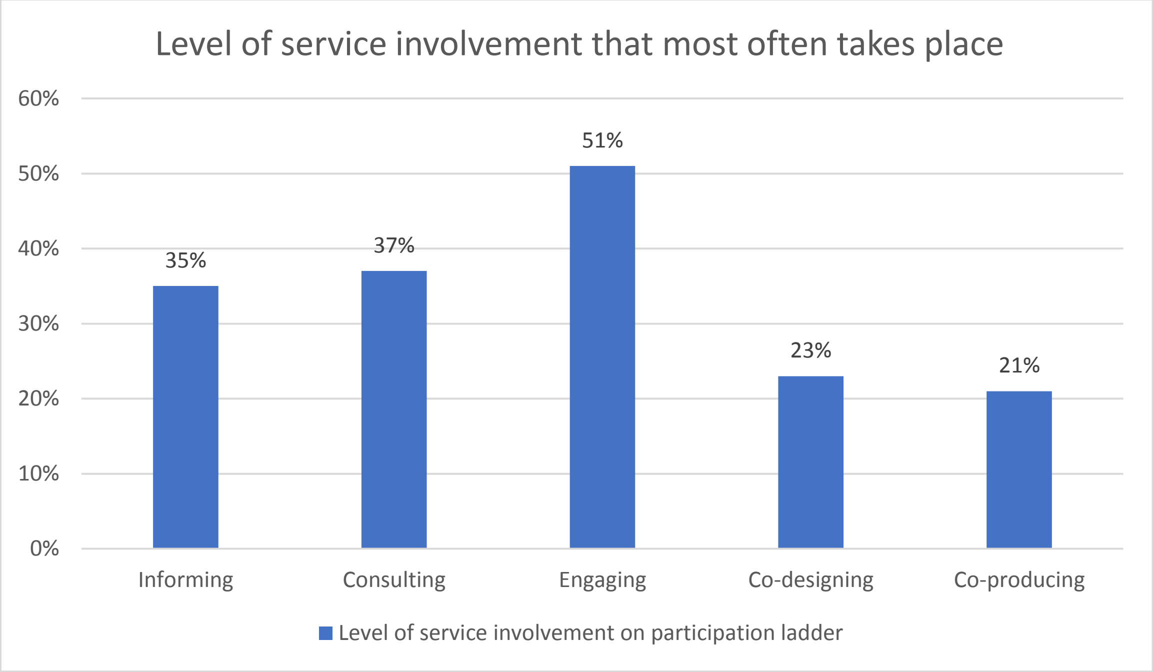

Figure 4.2: Level of service involvement on the Participation Ladder

Further insights into the depth of involvement can be garnered from the methods and means of engagement employed in these activities. The use of particularly innovative methods were described by some focus group participants. For example, one individual described the use of photovoice (or photo elicitation) to achieve greater inclusion for those considered especially disenfranchised.

> *... recently we've done a project with photovoice, so we're finding ways that we can hear the voice of and understand the experience of people without them having to sit on a committee you know, in some way as a pseudo representative of lived experience when they may not even have a group they're going back to.* (FG.SP.MH)

But for the most part, focus group participants described a more general range of strategies across services with the different population groups. This included individual level planning, in the form of personal care plan development, feedback forums, service 'exit' interviews, patient experience surveys. With reference to Figure 4.3, the survey findings indicate a detailed breakdown of the most common approaches, with many of these strategies suggesting a lighter degree of engagement. Comment boxes or questionnaires were the most frequently reported means of involvement (51%), followed by focus group discussions (41%) and the inclusion of those with lived experience on committees and boards (37%). These methods varied a little across the population groups with the migrant and Traveller service providers reporting 'including people on committees and boards' as their most frequent form of service involvement (71% and 75% respectively). For the Travellers group, 75 per cent also said they use focus group discussions, which was the second most chosen method by the migrant group (65%). For the Traveller group, peer research was the next most popular method (63%), whereas for the migrant group, workshops came in third place (47%). There were also some differences across organisation type. Public sector organisations were twice as likely as Section 39 organisations and NGOs to engage in service development or service reform projects (26% vs. 13%), while NGOs were more likely to utilise comment boxes or surveys, and deliberative workshops, than the former. In addition, the smallest organisations (fewer than 20 personnel) showed a clear preference for utilizing deliberative workshops (52%) and focus group discussions (48%), while the preference of the largest organisations (over 500 personnel) was for panels of lived experience participants (32%), online forums (27%), and service development or reform projects (23%).

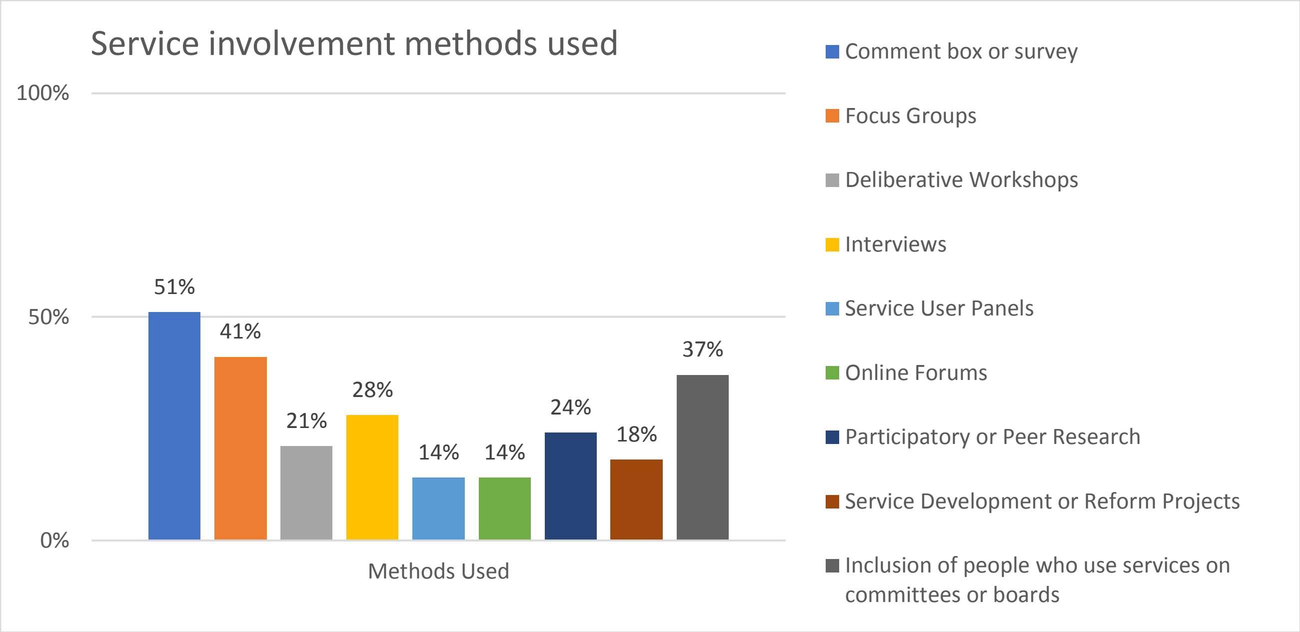

Figure 4.3: Service involvement methods used in respondents' organisations or units

Third, focus group and survey findings demonstrated that there was some distinction with respect to how service involvement was employed across the levels of the health and social care system. Focus group participants in the mental health, homeless, and drug and alcohol sectors discussed how, in their experience, service involvement encompassed activities at a range of scales. At the broader system and organisational levels, examples included the involvement of lived experience participants in national policy development and in strategic planning (e.g. board of management membership; patient charter development). Nevertheless, participants across all groups emphasized it was at the individual level where service involvement activities were most evident. This included the involvement of those with lived experience as peer workers in supporting the delivery of services. As such, some participants spoke about a gap around involvement activities in higher-level decision making where a lived experience perspective was often most necessary. This is illustrated by the following quote from a service-provider participant working in Traveller health:

> *And to make the change, I would love to see a Traveller champion at the higher levels in the HSE. I would love to see a Traveller sitting around the table at senior management level and they're having their discussions and trying to bring the real concept or the real lived experience of Travellers to the people at that table and change the thinking. And I think then you would work down through the system and change the thinking all over the place.* (FG.SP.TR)

Similarly, survey respondents reported service involvement was more likely to focus on the operational and coordination level (76%), rather than the overall strategic mission or governance level (58%). Service involvement was also reported as being more likely to be conducted in support of service implementation and delivery (83%) rather than service monitoring and evaluation (62%), or in relation to service design and development (56%). These patterns are robust across the different population groups, suggesting that by and large service involvement is used to support operational rather than strategic processes and functions.

Fourth, and critically, service providers pointed to how the current state of service involvement with the five population groups is largely uncoordinated. Some focus group participants referred to the disjointed engagement efforts within their organisations in this regard. Many participants noted a more systemic deficit and how the lack of a joined-up approach across the care system characterised much of the current service involvement. In many instances, providers felt that organisations working in support of the population groups were undertaking these activities in isolation, and were left to develop and manage involvement programmes on their own:

> *Yeah, like I mean I think from my perspective, like I think we've an awful lot of work to do in Ireland…I think for homeless services it's kind of left to each individual service to do it. So there's no kind of wider joined up kind of piece around people's experiences of being in homeless services, or feeding into consultations, or whatever it might be.* (FG.SP.HO)

As a result of this overall state of engagement activity, a large number of service provider focus groups participants asserted that service involvement was not sufficiently mainstream within services for the five populations. Echoing the experiences of some national stakeholders, it was in this light that participants appeared frustrated at the lack of progress in their areas. This frustration was again perhaps most evident amongst those participants working in the provision of mental health services, given what some individuals described as the level of historic effort invested in attempting to progress engagement, without significant change. For those providing services to certain groups, such as migrant, minority ethnic and Roma individuals, and to people experiencing homelessness, there still appeared to be a focus on trying to build momentum in service involvement, rather than on more advanced 'good' engagement practice.

4.3 Lived Experience Perspective

In general, and across the 15 focus group discussions and the 35 interviews with members of the five populations, direct experiences of service involvement were limited. Despite many individuals wishing for services to operate differently, participants reported only rarely, or having never been given the opportunity to provide feedback in relation to their services, or in relation the development of a new service. A number of focus group and interview participants stated that their first opportunity to discuss their views and their service-related and relevant life-course experiences was in fact this research study. As this person describes, who had used his particular service for three years, this meant there had been little chance to help improve their service experience.

> *…this is the first time that I've ever gotten to speak about my experience with [my services]. My first time ever… but I've never gotten to talk… like talk about my experience with [my services] to anyone other than like my friends or my parents. And my friends and my parents can't really do anything about it [improving services] …*(FG.PWLE.MH.CA)

For those lived experience participants who had never heard of or had never come into contact with service involvement processes or activities, there was often a focus on issues around services and service access, and the quality of their experiences in these interactions. Participants in each of the population groups contrasted the notion of service involvement with these experiences, where they felt that they had not being consulted or properly listened to when in receipt of services. One interviewee, who was experiencing homelessness, spoke about this in the context of accessing acute mental health care, when he felt he had not been listened to and as such, his needs were not taken seriously:

> *Any time I go out to the regional hospital… I wait 12 hours maybe at least and then…the people off the psychiatric part, they come up to see you – like the questions they ask you is like, 'What brought you out to A & E?' …And like the 12 hours that you're waiting, you're thinking… your thoughts are racing because you're thinking like, 'What am I going to say'. Hopefully you make them understand how badly I need help…They make you feel embarrassed for coming out there. They make you feel embarrassed for coming out and they make you, and then they'll ask you a question and just say I'll talk for 5 – 10 minutes about it and what are the problems going on in my life or my head and why I'm there – Then, instead of asking you a question about what you've been talking about, they'll ask you a question completely got to do with nothing with what you've said, and then after that happens three or four times, you start to get a bit pissed off…They're trying to distract you with questions that have nothing got to do with your problems...I feel like there's no point any more of going out there because it's a waste of time. It's a waste of time.* (IN.PWLE.HO.01)

Almost all participants highlighted times when their experiences of using or trying to access services lowered the sort of expectations and ambitions that involvement should foster.

Of those who had direct experiences of service involvement, consultations regarding individual-level care planning were often the most commonly cited example. Participant accounts illustrated how these experiences range from positive consultations – where participants felt they were in control of their care decisions and where the process had been useful – to negative consultations – where participants felt the process reinforced their sense of not being heard and was of little benefit. Some interviewees explained how their care planning process was driven by others with little consideration of their agency or voice. This interviewee from the Traveller community highlights one such situation, where he felt the professionals in the room were developing a care plan based on what they, and not what he, wanted:

> *I was in this position myself when I first went to counselling [ ] when my partner died… and a friend had brought me. And she was advocating for me and she was*

> *explaining everything to the counsellors…So yeah, there was the four of them [professionals], there was my friend and myself and they [the professionals] were trying to put a plan in action and what way they wanted to go forward and stuff.* (IN.PWLE.TR.05)

Beyond individual-level care consultations, participants' direct experiences of service involvement tended to involve once-off opportunities to provide feedback on a service, with participants sometimes not entirely clear on the purpose of such engagements or how their information was used. A small number of lived experience participants had taken part in qualitative engagements, such as interviews or workshops. But even in these cases participants felt that there was ultimately a failure to really listen to their views, betraying the low level of value placed on their input by decision-makers. This is exemplified by the following quote by a lived experience interviewee who had participated in a multi-stakeholder meeting on an emerging drug trend in which she had been involved:

> *I actually found like dealing with [a HSE service representative] is like banging your head off a brick wall…I didn't feel heard...The people from [charity name] at the meeting, they heard me. I didn't even have to say much because we were all like on the one level kind of thing… Like the NGOs listen to people, but the HSE, no.* (IN.PWLE.DA.01)

A small number of lived experience participants did mention having encountered peer workers, and this was discussed in a largely positive way. One interviewee noted how involving someone with similar experiences encouraged trust and openness. A Traveller focus group participant also noted how services had been improved by Traveller community health workers highlighting issues at a grassroots level to service providers. However, in the main, those with experiences of service involvement described how less in-depth activities, such as surveys, were in their experience a more common means of gathering lived perspectives.

4.4 Key Messages

1. Service involvement activity has been growing in recent years for the population groups in this study, and sometimes reported at very high levels. But this growth has occurred relative to a low base, and often involves engagement that is of lower quality.
2. The potential for effective service involvement with the five population groups is recognised by national-level stakeholders, but there is frustration around a lack of progress and coordination, and around other barriers such as complexity of the care system, tokenistic involvement, and a lack of implementation.
3. Overall, while there is variation across groups, many service provider participants report that service involvement often happens more at the middle 'engaging' level, or at the lower 'consulting' and 'informing' levels, than at the levels of ‘co-producing’ or ‘co-creation’.
4. Service providers also noted that service involvement activities are often uncoordinated, and conducted in isolation, with engagement being involvement in name only with little impact on decision making.
5. Many lived experience participants had rarely or never been asked for their views, and if they had, their participation tended to be on the shallower end of activities (e.g. once-off, survey or comment boxes).

6. Many of the lived experience participants described experiences with services, which represent the opposite of effective service involvement, wherein they were not respected, or listened to and were treated in a disempowering way.

Peer Research Case Study 3 – Mental health and lived experience in Service Involvement

By Martin Slevin and Kate Vickers

Kate and Martin investigated some of the elements that support meaningful engagement and make services more empathetic within the environments of the service centres they use: Martin's Day Centre, Croi Oir and Kate's school, Linn Dara.

Delivering an empathetic service – *Martin (with editorial support from ICSG researchers)*

I chose this [first] photo to highlight how this service explores the skills and talents of clients. Nearly everyone choosing to use this service can find a way to express themselves through arts and crafts. It shows that nobody needs to be excluded – everyone is welcome, and who knows what hidden talents may be discovered?

I chose this [second] photo to show how we all got together to build this polytunnel, and to show how much the gardening slot means to us. The photo shows how the delivery of a service like this can encourage interaction and activity amongst clients and produce good results. Many hands make light work. It takes a lot of co-operation to keep the garden tidy and thriving.

Key message: *All my photos were taken at my day-care centre, which I believe is very much a client-centred approach to participation in the service offered to us. The pictures show how we all participate in activities which are positive to good mental health progression. This, to me highlights something I find innovative in the HSE approach to delivering an empathetic service. All these activities encourage dialogue and interaction between clients and staff and give people the incentive to make themselves less isolated but more involved. To improve one's mental health we need to mix, mingle and discuss. For far too long we have conformed to the age-old norm – 'isolate and suffer alone', (self-stigma etc).*

Having a safe space – *Kate (with editorial support from ICSG researchers)*

I took this photo on a sunny day, and I think it shows a calming atmosphere and lots of nature. It's a good spot for your mental health. It shows a way of providing a space that is small, calming and accessible for people struggling with mental health issues. It provides a safe and calming outdoor space. I always feel comfortable and we have a communal garden we all built together. It's an area someone can go to calm down and get some fresh air. It's a way to get people involved in creating their own space, planting their own plants and having a safe space for the community.

I took this [second] photo because it was the place I first came in to in Linn Dara. It has comfy seats and a teamwork project mural on the wall. It's a communal area and a place people get together and play games or have meetings.

This photo shows an easy service that can be put in place – the comfortable couches and cushions and blankets and the community lunch area. People sometimes have a nap here during the day. I used to be nervous going into this room for meetings and interviews, but now I feel comfortable and safe here. It speaks for a sense of creativity and community as we all painted the mural together and we always play games here. It's good for my mental health.

Key message: *Together, the two pictures are safe spaces for me. I think every institution – schools, hospitals, colleges etc. should have a safe place like this. Somewhere someone can go by themselves, or with someone, where they can relax and calm down in a world of panic. These types of spaces are essential for people with anxiety to relax and settle. One room is a garden space I can get fresh air and one room is a space I can lie down and relax. Small private sensory rooms similar to these are vital to some people, so I think there should be more safe spaces like these.*

Conclusion – *Martin and Kate*

We think that both our organisations highlight the ways in which service providers can improve upon the delivery of mental health services by including and involving the community, and listening to our needs empathetically. Small, but meaningful additions to how services are delivered, as well as what is on offer makes all the difference to our levels of confidence.

5. Understandings of Service Involvement for the Five Populations

This chapter presents the views of participants across all research strands on their understanding of service involvement for the five population groups. Given the inconsistencies raised in Chapter 4 regarding terminology and approaches, it is important to compare the views of the different sets of study informants. The chapter is divided into two sections. Findings will be first presented on the meanings of service involvement and the sort of values that should underpin these activities. Findings on the goals service involvement should aim to achieve will then be described. Within these two sections, and in line with the preceding chapter, the findings will be organised by each of the informant groups: national-level stakeholders (based on interview data); service-provider participants (based on focus group and survey data); those with lived experience (focus group discussions; individual interviews).

5.1 Meanings and Values of Service Involvement

5.1.1 National-level stakeholder perspective

National stakeholders viewed service involvement as a concept and process which should exist at various levels within the general health and social care system. As such a number of interviewees noted how those who use services should be involved at all levels as this quote from a coordinator of acute care services illustrates:

> *But I don't think it's enough just to have a few people at national level… So, we would always recommend that our* [individual organisations] *have service users involved at that level as well, and at* [the overall] *group level… so people who are working at national level don't feel they have to speak for everyone in the system. There are actually patients at every level inputting into the design of our services or how we deliver them.* (IN.SH.01)

National stakeholders also understood service involvement to comprise of different forms of engagement across a spectrum of activities. Some interviewees argued that such a spectrum ranged from least effective or inappropriate (and therefore tokenistic) approaches, to the most effective and appropriate modes (for example in a co-production approach). Others had a more flexible view stating that the activities should depend on the context and the purpose of involvement. For example, one stakeholder felt that the scope of involvement for those with lived experience should reflect the nature, or urgency, of each situation:

> *Now…*[the use/nature of service involvement]*…obviously will be a balance and some people will… for some situations it'll be more relevant than others. If somebody has say a brain aneurysm and needs an operation, well you know it's… the clinical staff obviously have to do what they need to do, and sometimes they need to do it very, very quickly. But in the… in say mental health issues or addiction issues there's a much greater scope for the participation of individuals in their own management.* (IN.SH.02)

There was a general consensus among interviewees that those with lived experience should be the key stakeholders in the design and delivery of services and they should consequently have a strategic role in the development of services. Stakeholders felt that those with lived experience not only had specialist knowledge, but may also ask 'awkward' questions which others may not. One interviewee declared that including those with lived experience in the services was a matter of fundamental rights, which had the potential to '*…level the playing field…*' (IN.SH.06). As such, interviewees argued that a collaborative partnership with those with lived experience underpins effective involvement:

> *But equal partners you know. We're experts in the area we work in but the patient is an expert in their own experience and their own lives, you know. So, certainly coming together as equal partners would be really important.* (IN.SH.01)

In terms of core values, some interviewees stated that effective service involvement should be guided by ideas and principles of compassion, respect, understanding and support. In this way, involvement should strive to be both inclusive and person-centred. A number of stakeholders noted that service involvement should be empowering, involving people with lived experience in developing solutions to the problems which affect them. These points are illustrated by the following quote, in which a stakeholder interviewee who has worked to advance a partnership approach with the Traveller community acknowledges that while such values should drive service involvement, it is not always the case:

> *Yeah I mean it's quite complex I suppose you know particularly for marginalised groups, such as Travellers and Roma. So the idea of user involvement with active participation, you know empowerment, engagement, collaboration, those particular terms that really I suppose reaffirm that partnership approach. But you know I suppose the reality isn't always the case you know when groups – when outcomes and in particular outcomes and inequality of access participation outcomes is the reality say for Travellers and Roma that you know that idea around patient and public engagement is… not necessarily the reality or it doesn't I suppose live up to the golden standard. So those are the key principles and values that from our understanding would underpin that vision around what patient engagement would look like.* (IN.SH.08)

5.1.2 Service provider perspective

Three key themes emerged when analysing service providers' views on the meaning of service involvement. First, for some service providers, voice was a core element. This is illustrated by the following quote from a service provider in the drug and alcohol sector:

> *I suppose the most basic service user involvement would be somebody is really involved in their care plan and has a voice in developing their care plan and it's not developed for them. It's developed with them and.. it's a joint need with regard to whoever's managing their care and then all the way up to having a real input and kind of a co-production strategy with regard to delivering services or having a say in services that are needed or developed but there's various stages along the way. (FG.SP.DA)*

For a number of participants, an engagement demonstrator of the voice of lived experience participants was peer involvement. This was discussed in the majority of the service provider focus groups, where participants equated peer support, or embedded peer voices as a constituent part of service involvement.

Second, there was consensus across all five provider group discussions that this 'broad' understanding takes in involvement of different levels, and again includes the individual care level, the organisational level with respect to day-to-day service delivery, and the highest strategic levels to have trickle down effects and real impact. This multi-scalar view is illustrated by the following quote from a service provider working in mental health services:

> *My understanding in terms of the I suppose people with lived experience involvement is that it's both at an individual level which refers to what* [named participant] *said about that menu of options and navigating yourself through the system. And then there's also the organisational aspect which is that everything we do is I suppose both the decision on what to do, the designing how to do it, the implementation and the valuation of it…*(FG.SP.MH)

The results of the survey supported this view of involvement being across different levels, but also allowed for the identification of a ranked order of these levels. **Error! Reference source not found.** demonstrates that over half of respondents reported that involvement focuses on the organisational process of individual care planning (53%). Slightly more respondents view it as focusing on organisations' overall strategic mission, ethos, and governance (64%). However, a higher proportion of respondents felt involvement concerned the operation and coordination level, or the running of services (77%). Furthermore, as is illustrated by Figure 5.2, while almost two-thirds of survey respondents consider service involvement to focus on service design and development (62%), and service monitoring and evaluation (62%), much more (82%) felt it focused on service implementation and delivery. These figures are largely in line with data presented in Section 4.2 on what organisations' involvement activities *actually* focuses on.

Figure 5.1: Processes of service involvement

Third, service provider participants believed that service involvement was characteristically varied in its application and nature: it can take place at different times on a service-use journey; it can be applied to clinical topics and processes or psycho-socially focused; it can be formal or informal. The consensus on this appeared to be that the wide spectrum upon which service involvement activities are based is a positive, providing for multiple and varied pathways which open the door for flexible and inclusive approaches. Inclusion (and diversity and equity) were ranked highly in the service provider survey (chosen by 50 per cent of respondents), coming in as the second most selected principle underpinning service involvement (second only to 'right to be involved', which is discussed more below). However, for the homeless, migrant, minority ethnic and Roma, and Traveller groups, they felt this was the number one underpinning value. The most frequently ranked factors (chosen by 52 per cent of respondents) was 'Affording those who use services the right to be involved'. However, when broken down by the population groups, it was a greater number of respondents from organisations who provided mental health services and organisations that provided drugs and alcohol service that reported this as the core underpinning principle for service involvement.

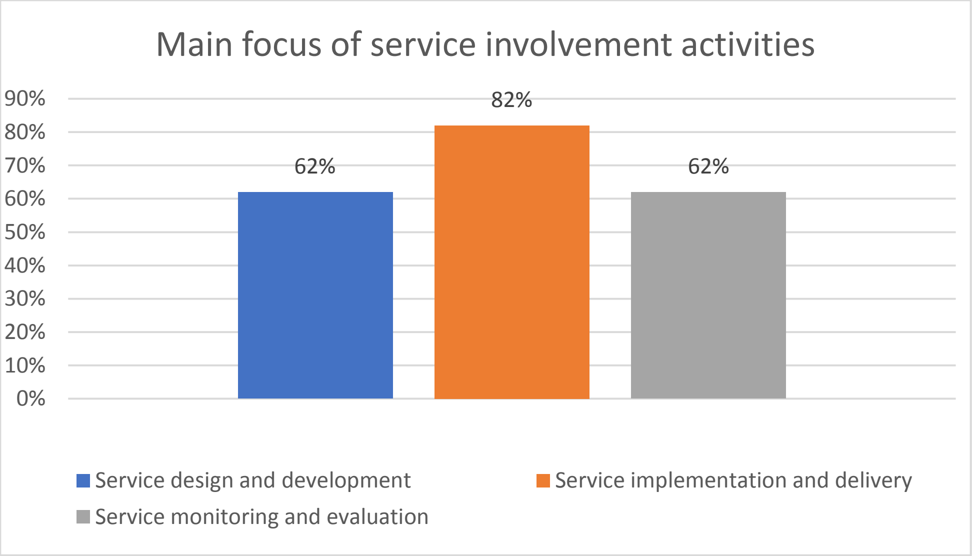

Figure 5.2: Focus of service involvement within organisations

5.1.3 People with lived experience

Given the lack of direct interaction with service involvement activities, it was not surprising that those with lived experience had the least familiarity with the concept, or related ideas regarding 'public and patient engagement' and 'public and patient involvement'. Amongst most of the participants in the majority of population groups, there was often only a limited understanding of what service involvement meant. Even after a general description was offered, many focus group and interview participants still found it challenging to grasp the meaning of involvement. This initially led to a conflation between service involvement and service use experiences, and necessitated a more detailed explanation involving examples of service involvement of different kinds (see section 2.2.2 for a description of these examples).

After discussing the general purpose of engagement, the majority of lived experience participants asserted that involvement was potentially a valuable process. This is illustrated by the following quote from a Traveller interviewee who described the usefulness of collaboration with respect to individual-level, multi-agency service planning:

> *I think it's absolutely amazing. I think it's brilliant… I think collaboration and sitting at a table making plans* [is essential], *because it helps as well, all services to be able to be on the same level with each other as well in relation to one person…it can be hard sometimes to get them all into the one room all the time. But when they do, I*

> *think it's really, really valuable.* (IN.PWLE.TR.04)

Participants saw value in service involvement because they believed it would provide an important opportunity for the voices of those with lived experience to be heard, and would help to build trust with service providers. Some participants also noted that group scenarios would give those who use services the chance to meet and relate to others with similar sets of experiences. However, across the majority of lived experience focus groups and interviews it was the belief that service involvement could result in positive change that was discussed as its most valuable dimension. In this manner, participation in service involvement activities was viewed by many as a means of 'giving back' and helping others. This is described by one interviewee in the context of his own recovery from the use of drugs and alcohol:

> *Well, as they say when I'm doing the 12-step* [recovery] *programme… 'we keep what we have by giving it away', and the twelfth step is helping others. So actually when I'm helping somebody else, I'm actually remembering, 'I used to be in that place', or whatever, and you get a feelgood factor from that like when you're helping obviously…Like you can sit back and do nothing, or you can get involved like. And I feel like if you don't really get involved with things, you'll not really progress yourself and you'll sit back and you're happy with a mediocre everything and you'll just pain and suffer. You know, you do need to step up and give, you know, sometimes do a wee bit more like.* (IN.PWLE.DA.02)

Nonetheless, a small proportion of lived experience focus group participants and interviewees viewed service involvement more negatively. Some opined that no action arises from the sorts of activities that are linked to service involvement, with a slim likelihood that outcomes would be achieved. Others, who may have conflated service involvement with 'complaining', noted that negative feedback can be taken personally by service providers (which they believed could negatively impact the care they received thereafter), while others felt it was not their place to be involved in the design or delivery of services. This was either because they were deferential to the expertise of service providers, and/or because they did not feel that they had a right to voice negative opinions because of their status or circumstances. This is illustrated by the following quote from an international protection applicant, who felt that as he was not a citizen of Ireland he did not have a right to complain about the services he received:

> *My right is in my country…I don't have… for me I don't have any rights… So, I'm living here for comfortably, for peace, so I don't like to complaining for anything, and I think I don't have the right. If I had the right, I would tell…my President, 'this is what I need'. Why disturbing the Irish?…*[our] *right is there, over there in Nigeria.* (FG.PWLE.MM.DP)

5.2 Goals of Service Involvement

5.2.1 National-level stakeholder perspective

National stakeholders generally felt that service involvement should have a number of goals, with the first of these encompassing a range of areas linked to improving the effectiveness and person-centeredness of services, and the efficiency and effectiveness of provision. Greater transparency in services, and creating more clarity around implementation decision-making, resource allocation and monitoring, was identified by several stakeholders as being key in this respect. For these interviewees enhanced transparency through service involvement activities offered a means to counter what they viewed as the systemic failings and scandals of the past. It was argued that as some of these failings have gained significant media attention (for example the Cervical Check scandal in Ireland) that there was an increased demand for the sort of engagement that service involvement promoted. One interviewee highlighted that service-involvement processes represented an important opportunity for proactive change-making, in place of reactionary processes arising out of litigation.

A second and related goal discussed by national stakeholders was that service involvement should help support a move away from a 'doctor knows best' and disease-centred approaches in health and social care services. Instead, stakeholders argued, involvement should foster a more patient-centred, and indeed holistic, service system – enhancing communication between service-providers and those with lived experience. This is illustrated by the following quote which posits that involvement should work to dismantle prevailing hierarchical models of care:

> *…it's about I suppose ensuring that services are...sensitive and receptive to people's needs or accommodating of people's needs, so you...try to look at services not from a top-down but from a user perspective...you need to rethink how you're going to provide your services here to come up with a different model.* (IN.SH.04)

Other goals of service involvement were linked more directly to outcomes for individuals. National-level stakeholders argued that better health and well-being outcomes should be a third key goal, and a natural consequence of service involvement, given that engagement activities should support more evidence-based, satisfactory, and safer services. This is illustrated by the following quote which describes positive health outcomes and the positive feedback loop arising from involvement in individual care planning.

> *And like all the evidence shows if you involve service users more in the conversation, they'll tell you what they're worried about, their treatment plan will be more applicable to them. They are more likely to adhere to it when they go home and they're less likely to be readmitted back into hospital. So, it's a win-win for everybody.* (IN.SH.01)

Finally, according to national stakeholders' better inclusion outcomes should be a key goal of service involvement. It was felt that service involvement processes can provide those with experiences of exclusion the opportunity to share their views and the feeling of having been listened to, along with a greater trust and confidence in care systems and service providers. This may reinforce health outcomes fostering greater engagement in the health system, better care plan adherence and greater health proactivity. Interviewees described how service involvement should help counteract discrimination and stigma that people with lived experience can face in the care system. In this regard, one interviewee noted that service involvement was an important tool in meeting the public sector's duty to uphold principles of equity and inclusion:

> *... public bodies have a statutory obligation to uphold those particular principles and values, and...we would certainly see that human rights, equality, inclusion, diversity should also be included...* (IN.SH.08)

5.2.2 Service provider perspective

In general, there was good alignment between the perspective of service providers and that of national stakeholders, albeit that providers were more likely to elaborate goals in relation to on-the ground circumstances and scenarios. There was also alignment between those goals identified by service providers within the survey and those discussed and prioritised by those within the focus group discussions.

First, optimising health, inclusion and recovery outcomes of those who use services was identified as a key goal of service involvement by service providers. This was the highest ranked goal within the survey, with 64 per cent of survey respondents identifying it as being an important goal. In the focus groups, participants discussed how effective service involvement should lead to a focus on well-being and preventative health treatments, and should facilitate improved recovery outcomes. Service involvement was therefore seen as an important mechanism in securing better health. But providers also discussed how service involvement should enhance the quality of life of the five populations overall, and leverage improvements in the lives of individual members of the groups more broadly. In this manner, participants emphasized the need for better inclusion, where the needs of diverse individuals can be more readily addressed through a culture that supports involvement. This was again because of the entrenched forms of exclusion that many service providers considered to characterize the lives of some of the groups. For some service-provider participants, and as noted here by a Traveller service provider, it was jointly better health and inclusion outcomes that represented the fundamental goal that should drive service involvement:

> *I think if you get better health and inclusion outcomes, it kind of encompasses everything else. And I suppose I'm thinking from public health nursing, you know, from like, antenatal right through to end of life care. If we can get that all much better, that's what we're looking for, isn't it?* (FG.SP.TR)

Second, it was highlighted that service involvement processes should allow for gaining the unique perspective of people with lived experience- – whether it is people who use services themselves, or their family members or carers. Fifty-eight per cent of respondents had identified this goal as important within the service provider survey, with little variability across those delivering services to the different population groups. Capturing this perspective was described by providers as giving critical first-hand experiential knowledge, which offered a valuable contrast to service providers' practice knowledge. A number of participants across the different focus groups argued that people with lived experience will have the best insight into their own situations and needs, and whether a new service or a service adjustment will work. But several providers also described how these perspectives must reflect the full range of sub-groups within a specific population. They must therefore include a diverse range of people, with an inclusive approach taken to gathering views and opinions. One service provider focus group participant argued that barriers should be removed for inclusion. This was in the context of discussions on a 'one size fits all' approach, which they argued did not work to include those who are marginalised. Moreover, it was asserted that engagement should bring about actual change at a deep and meaningful level and not just serve as involvement *per se:*

> *...I do see service user involvement of more of a collaboration than a one-way process where we invite people in, or we involve them. We really need to be moving to the level where we are working together and we're collaborating. So, it's not all about our agenda or the agenda that the service or that the HSE as an organisation, we*

> *need to listen to each other so that we have a common agenda and common goals.* (IN.SH.05)

Third, improving relationships and helping equalise power between service providers and people who use services was identified by 57 per cent of survey respondents as being an important goal for service involvement. Focus group participants outlined how an outcome of eliciting lived experience perspectives is likely to be a shift in the current culture, where power was considered to be held unequally by those providing services. Several of these participants advocated for an equalizing approach to service involvement where respect and empathy are central, and 'us' versus 'them' thinking is discarded in favour of a partnership approach. One participant warned against dichotomous perspectives on who should be listened to. Many participants emphasized the importance of using service involvement to break down hierarchies between service providers and those who use services. This would help creating a stronger feeling of control amongst members of the five populations with respect to the health and social care environment, and again build greater trust in services. Focus group participants argued that those with lived experience should be regarded as experts by virtue of this lived experience, and for this reason respect and due regard should be given to the value of their contributions in service design and development. Indeed service-provider focus group participants emphasized the importance and transformative potential of 'good' involvement, as this quote from a service provider working in homeless services illustrates:

> *But I think one of the things is around ensuring that the service-users' voice is heard, and that they see themselves reflected in the environment, and that they feel that they have control over the environment, and… it's not a superficial level, that it's at a deep and meaningful level...and it's creating that culture, and the biggest thing is around that power imbalance and being really aware in order to have that really good involvement. (FG.SP.HO)*

Fourth, and as a goal closely related to the previous two, providers highlighted how making those with lived experience feel heard is key, with 49 per cent of survey respondents reporting that this was important. According to some focus group participants, being 'heard' can provide those with lived experience with a feeling of being valued and empowered, even outside of the service arena. The following quote from a service provider from the drug and alcohol sector illustrates their experience of some lived experience participants getting value from the process of taking part in a service involvement exercise:

> *...we've had an opportunity to develop a patient charter or service user charter, but we actually travelled to all the various sites to get input there. Now, it was minimal but at least we gave people an opportunity and then we got a service user representative group to kind of have a look at it as well...those people...were quite I suppose pleased that their work then was hanging on a wall... (FG.SP.DA)*

Ultimately this goal, and many of the others, was about how service involvement can help support better services. Facilitating those with lived experience to be heard can be used as a structured process to help gain a better understanding of needs and what changes are necessary:

> *…when they access that service you know that they're equal like (participant) just said they're involved, they're very much, is their journey, it's not ours but 100 per cent*

> *what* [named participant] *said like their active involvement and telling us what we're doing right and what's not so good and needs changing…* (FG.SP.DA)

Finally, a range of other goals was mentioned across the focus group discussions as being important, but not with the same frequency nor consistency as the first four. A number of participants suggested that a goal of service involvement should be to support the monitoring of effectiveness in services. It was argued that this may provide a user-informed means of holding services to account, or to direct investment towards particular areas. Other participants suggested that a goal should be to enhance effective communication around services, specifically regarding more suitable language and terminology. It was also posited that service involvement would feed into more culturally safe services, by providing service providers a greater understanding around experiences of discrimination, as well as around the cultures of different nationalities, races, and ethnicities.

5.2.3 People with lived experience

Although again people with lived experience broadly highlighted similar goals to national stakeholders and service providers, the views of the members of the five populations were clearly grounded within their service experiences. In this manner, goals of service involvement were linked to supporting service features that they considered to have worked well for them in the past or, perhaps more often, linked to factors that responded to particular absences in the quality of their services.

According to the vast majority of lived experience participants across the focus groups and interviews in this study, the first and by far the most important goal of service involvement should be to improve services, and health and inclusion outcomes. Better services and better outcomes were inextricably linked in most participants' minds, and were thus framed as one core goal. Many individuals felt discussing better services in isolation was meaningless if this did not lead to better health outcomes or leverage greater inclusion for them and their peers. A number of participants contextualised their emphasis on this goal within their own circumstances and histories including, again, their negative experiences of service provision, but also their health and inclusion challenges. The following quote from a woman who used homeless services, illustrates how she saw a clear relationship between service involvement and having the capacity to improve services and generate specific benefits and impacts for individuals:

> *… I think* [a goal of service involvement is]*…to improve their service, you know, what people's thoughts and opinions and how can they make it better, you know…Just to see how things are working and if it's not working, then they need to change something and then it's about other people's opinions because you could make a change and it could be even more, like even less beneficial to someone, you know. I think it's important to get other people's opinions* (IN.PWLE.HO.07)

The second goal dominant amongst the views of the five population groups in this research concerned gaining the perspective of those with lived experience. However, in this case participants emphasised that it was not just about gaining a perspective, but it was about ensuring that it was a diverse set of perspectives. Right across the five populations, participants noted the heterogeneity of individuals and sub-populations within their groups. They recognised that there can be vastly different experiences within groups, such as those due to differing ethnicities and immigration status for migrant, minority ethnic and Roma, or those due to using different kinds of drugs and or to membership of different drug subcultures for drug and alcohol groups. This is the view illustrated by the following quote from a migrant participant who is describing the value of service involvement workshops he participates in with people from different communities:

> *… those workshops* [I take part in], *we have the one goal and then like a ten people …A lot of different experiences and then I can point out the one view and then the other person bringing out the totally different point of view, you know…Yes, so that means, because we have so many different communities and then those other communities – Peruvian, Venezuelan, Filipino, Mongolian, Chinese, Mexican, and then we gathered those people together and then running the ideas.* (IN.PWLE.MM.02)

A third and related goal identified by lived experience participants was linked to enhancing cultural understanding and cultural competence. Highlighted by members of the migrant, minority ethnic and Roma group, and members of the Traveller community, participants argued that approaches should be inclusive of minorities. Therefore, the process and outcomes of involvement should aim to recognise, celebrate, and promote minority identities, rather than overlooking them or framing them as burdensome. In this respect, several participants in these groups expressed a desire for involvement to nurture cultural understanding and by extension cultural competency for those who provide services:

> …[It's important] *to have somebody there that understands Traveller culture and a lot of the time too, a member from the Traveller community themselves works really well in engaging Travellers with any service.* (IN.PWLE.TR.04)

The fourth goal of service involvement which lived experience participants discussed was about feeling listened to and valued. Again, participants noted the connection between such feelings and a greater sense of being included and empowered. For many individuals, this would help counter and respond to their experiences of not feeling heard, not feeling valued, or included, and being disempowered. A man who had used mental health services discussed how he and his peers felt seen, heard and respected having been involved in a service involvement workshop and highlighted:

> *I thought it was a positive thing, you know, because they weren't just, they were engaging with you as a person. They were recognising that even though (participant name) is not himself, even though he's depressed, even though he's anxious and he's breaking out in a sweat when we're talking to him, he's still able to engage with us. He's still there, he's a real, intelligent man, he's not dense.* (IN.PWLE.MH.04)

One participant from the Traveller community, however, rejected the goal of 'feeling heard' as insufficient and '…*patronising, very patronising*…' (IN.PWLE.TR.DU). For him, it was much more important for service involvement to impact the lives of people in more essential ways, given what he felt was the major deficiencies in care for Travellers, especially in relation to mental health supports.

5.3 Key Messages

1. There was broad consensus across national stakeholders, service providers and those with lived experience on the meaning and goals of service involvement for the five

populations, with agreement that involvement could offer a valuable means for these groups to have their voices heard.

2. National stakeholders and service providers largely viewed service involvement as being a flexible concept and as a multi-scalar activity which operates at different levels, and which incorporates a spectrum of methods.
3. Many lived experience participants in this study were unfamiliar with the concept of service involvement, or erroneously conflated it with ‘complaining’.
4. Common values, across all study informants, related to involvement being about rights, inclusion, compassion, respect and understanding.
5. Common goals of service involvement were identified across all study informants and included creating better and more effective services and service delivery, and better health and inclusion outcomes.
6. For the most part, national level stakeholders perceived service involvement as relating to big agendas and systemic change, for example moves towards greater transparency in services, Public Sector Equality and Human Rights Duty, and more person-centred care.
7. Service providers and those with lived experience emphasised that key goals of service involvement should also be about capturing the unique and diverse perspectives of those with lived experience, making them feel listened to, valued and empowered.
8. Lived experience participants, particularly those from Traveller and migrant backgrounds noted a goal of service involvement is, or should be, enhancing cultural understanding and cultural competence.

Peer Research Case Study 4 – Service Involvement for migrant, minority ethnic and Roma communities

By Vusi Thabethe and Patrycja Cichocka

We highlight the absence of effective service involvement for Migrant communities in Ireland. We have focused on the barriers that prevent Migrant involvement in the process of service provision. I, Vusi examine these barriers in the light of Direct Provision; and I, Patrycja examine the barriers caused by a lack of cultural competence.

Recognising barriers to service involvement – *Vusi (with editorial support from ICSG researchers)*

I took this photo of a Direct Provision centre as it catches the image of an environment where parents have to keep their children upstairs because it is not safe outside, for example the old, rusted pole, which is very dangerous for children. The photo underscores the carelessness, no duty of care, and the circumstances of allowing 'for-profit' organisations to look after vulnerable people.

This photo shows the view from the building, and how it is wasted because people in there (the Direct Provision centre) do not feel safe, and feel unwelcomed, due to treatment. This addresses health and well-being, mental health and depression..

Key Message: *Together, the message that my photos convey are the unsafe treatment of the people living in Direct Provision and a lack of consultation with them about needs. There are no services implemented to help people feel included and welcome and no efforts to listen to them. There seems to be no sense of empathy for the usually traumatised people. It appears that these issues are mostly caused by an industry which is only focused on one thing and one thing only, generating as much profit as possible.*

Bringing down the barriers to inter-cultural communication – *Patrycja (with editorial support from ICSG researchers)*

This photo illustrates the barriers in accessing and understanding services. Also, the barriers to communication, such as stereotyping and bias. There are many cultural and language barriers to cross and acknowledging them and understanding them is crucial. The photo underscores a wide range of barriers that migrants are facing in being involved in decision-making based on lived experience. Migrants are all different nationalities, so more open discussion about personal circumstances and different attitudes towards power and hierarchy is needed. For example, emphasising someone's background could be a sign of respect, but could also make others feel deeply uncomfortable. If service involvement was done with more respect and empathy it would be better.

Based on personal experience, using technology might aid in bridging intercultural language barriers. Sometimes both communication partners are unaware that misunderstanding and miscommunication is even happening. The use of technology might be perceived as to improve communication or language barriers. The endless discussion (through Google Translates) makes people impatient, but patience it is a key for better communication and understanding one another.

Key Message: *Better involvement in the services should be created to prevent invisible misunderstandings in inter-cultural communication. It starts with our ability to see the world through different eyes, to shift our perspective, to overcome our bias, recognise that we need a shared basis of understanding to create a code of meaningful communication. Cultural competence is the ability of a person to effectively interact, work, and develop meaningful relationships with people of various backgrounds.*

Conclusion – Vusi and Patrycja

All four photos suggest a lack of service involvement and cultural understanding between service providers and service users. Many using Direct Provision services feel excluded from decision-making that could make them feel more welcome and safe. Similarly, the well-being of Migrant communities could be improved by the integration of cultural competence into the delivery of services that would be more empathetic to Migrant needs.

6. Challenges for Service Involvement for the Five Populations

This chapter presents research findings on the challenges that impact the effectiveness of service involvement for the five population groups in Ireland. These findings provide insight into the factors that, which when lacking, underlie issues related to the quality and consistency of engagement described in Chapter 4. When these factors are in place, or when they are accounted for, they are likely to help to achieve the goals of engagement outlined in Chapter 5. With reference to Figure 6.1, five key challenges were identified: 1) leadership and commitment; 2) implementation and action; 3) population capacities; 4) trust; and 5) representation, stigma and discrimination. While the first two challenges can be broadly understood as factors encountered at the strategic and organisational level, and the remaining three as factors encountered at the individual level, each challenge had clear links to and were observable within all levels of the health and social care system, and its public and patient engagement environment. The influence of these challenges were largely robust across all five population groups, but any notable differences that were observed will be highlighted.

Findings on each challenge are drawn from all of the study's data-collection strands: the interviews with national stakeholders; the service provider focus groups and survey; and the focus groups and interviews with those with lived experience.

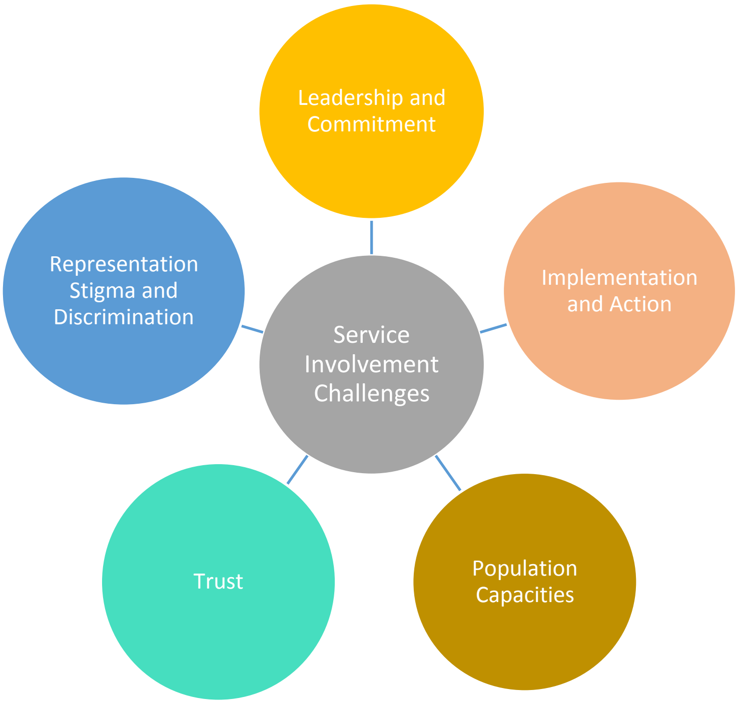

Figure 6.1: Key involvement challenges for service

6.1 Leadership and Commitment

It was evident that across all sets of study informants, but especially for national-level stakeholders and service provider participants, that leadership and commitment was considered a key factor influencing the effectiveness of service involvement for the groups. This was both at a national strategic level, but also at the level of regional and local organisations. Although positive examples were discussed, study participants were primarily concerned about perceived deficits and gaps in leadership and commitment. These deficits were often described as requiring urgent, if not the most urgent attention of all challenges, given that they could generate deficiencies downstream, such as issues related to the standardisation of terminology (see Chapter 4), and compound other challenges (presented later in this chapter) that impact the engagement effectiveness. Findings on leadership and commitment, as such, contextualise the broader ecosphere of engagement for the groups, and are presented across two dimensions: national strategic direction and prioritisation, and organisational processes and commitment.

6.1.1 National strategic direction and prioritisation

Some national stakeholders and service-provider focus group participants noted that to facilitate effective service involvement, systemic change was required, with leadership and prioritization needing to be demonstrated at the level of national policy and practice. For many informants this was about showing a clear commitment to supporting involvement for the five populations groups, and implementing a well-considered strategic direction that is established and led by senior levels within the HSE and government. Many of the stakeholder interviewees emphasised the importance of a strategy to drive, guide and inspire service involvement. Such strategies should be embedded into work plans from the highest levels to help generate activity and innovation in engagement:

> *Well, first of all, we need leadership support. We need leaders in the health service who see the value of service user involvement and we need to see modelling of that. That it's not just a concept, that it is something that is modelled and something that is practiced. And when we have you know, our colleagues who see something working for example, at national level, then they're more likely to say well look we can try replicate that or we can learn from your experience and do it locally and vice versa when we see something working locally. We can also learn from that experience. So, leadership support will be one and having, engaging staff to engage with patients, that would be another.* (IN.SH.05)

For service providers, there were concerns that there was little meaningful leadership and commitment coming from higher levels. A service provider in the drug and alcohol sector describes this lack of commitment from all but the smallest organisations, resulting in the responsibility for engagement activities often falling to those on-the-ground:

> *… so I would see the smaller agencies having better success in [service involvement], because they're smaller and it's possibly easier to explore and you know give supports and all that. But when you're looking at big organisations you really need strong leads and you really need service user involvement and engagement to be, look, higher up on the priority list of management and it's not. There are a few people on the management committee that they're the same people that just kind of are the ones that are looked to and, 'Oh so you are into that thing aren't you, would you look after that please?' But because we have our own discrete roles as well and it's not associated with service user involvement in the title, you're not taken seriously because people wonder well why is [this] person trying to do service user involvement stuff, why isn't it the manager. So I can see it working more successfully in smaller agencies but when you're looking at big agencies that cover you know a CHO or two CHOs like it's just tokenistic.* (FG.SP.DA)

These findings are supported by data from the service-provider survey, where almost a third (31%) of respondents did not agree that there was strategic high-level leadership and resources within the general health and social care sector to support service involvement. Furthermore, almost half of respondents (47%) felt that service involvement for the groups that they work with had not been given adequate attention within national government policy – with migrant (66%) and Traveller provider groups (75%) highlighting the lack of attention most. In addition, 46 per cent of respondents disagreed that service involvement had been sufficiently prioritised within the HSE for the populations their organisations work with; this was more of an issue for those working in mental health services than any of the other groups, where 61 per cent of respondents did not feel there was adequate prioritisation.

According to some informants, challenges regarding the absence of a focused policy and a strategy to enact that policy were compounded by the difficulties in navigating the crowded official document environment. Whether policies, strategies, frameworks or standards, participants spoke about the problems in knowing which document they should follow, and how it relates to the priorities laid out in other policies that they are required to follow. This quote from a national stakeholder points to this challenge and the need to be clear and concise in messaging:

> *I don't envy them [service coordinators] because there have been so many documents in this area and if I was a hospital manager, I would say oh my goodness, not another document...I think if a document comes out, it should be… I'd be going for slim! I'd be going for you know, as little information as is required, very easy to read, very concise and very clearly linking into everything that's already there. You know, so the last [thing] people want is to get a document and say but how does this link in with the National Standards for Safer Better Healthcare, how does this link in? Is this something totally different?...If we can find some way of streamlining what's already there and making it really easy for staff to implement, then it's more likely to be successful. And things have only gotten worse as a result of the pandemic, people are very tired. If we give them another document with another set of standards, I think it's going to go in the bin.* (IN.SH.01)

For those with lived experience, while participants did not address service involvement policy and strategy absences directly, several individuals across the groups felt that they were not considered within the strategic priorities set out by institutions and senior management at the highest levels of health and social care. This was both in general terms as individuals within the care system, and in terms of their views regarding the services they receive. A number of participants in a discussion with younger people using child and adolescent mental health services held this view, and is exemplified by this quote from a male participant:

> *Yeah, I just feel adolescents are sort of looked down upon sometimes, not all the time. It's sort of like we're not stupid, we've a lot to offer, we have a lot to say. Our opinions are valid as well.* (FG.PWLE.MH.CA)

In sum, it is fair to say that stakeholders, service providers and those with lived experience were concerned that there was insufficient high-level attention and prioritisation given to service involvement for these groups. Participants felt there was an absence of leadership to advance the development of engagement.

6.1.2 Organisational processes and commitment

In line with 6.1.1, there was a strong feeling amongst stakeholders and service providers that organisational buy-in was critical. Across all focus groups, service-provider participants asserted that service involvement should be placed high on organisational agendas. There was a number of reasons highlighted, including: the need to give visibility to the importance of service involvement; to help create an ethos of involvement within the organisations culture; and to commit to ensuring that involvement is embedded within the daily activities and overall strategic direction of the organisation.

Responses to the survey indicated that most respondents (78%) felt that there was strong leadership and a positive ethos of engagement to support involvement within their organisation, with 78 per cent also stating that the input of people who use services is valued within their organisation. Further, 84 per cent of respondents reported an openness and positive attitude towards service involvement amongst those working within their organisation. Nevertheless, almost a quarter of respondents (23%) felt that the level of internal leadership was not sufficient. This appears to be more of an issue for some of the organisation's serving certain population groups: 36 per cent of those working with those using mental health services, and 41 per cent of those working with migrants, minority ethnic or Roma believed this was a challenge. Across the focus groups, service providers were much more likely to draw attention to these sorts of issues. In fact, many providers in the group discussions spoke about the challenges in ensuring organisational buy-in, with several individuals noting that this was absent from some organisations. The following quote from a service provider in the drug and alcohol sector describes how they felt current involvement initiatives were tokenistic and ineffective, as they were not management-led:

> *I suppose I'd like to see stronger leadership and funding to support this. And not service user involvement or engagement being just kind of the added thing to the agenda if we have time or if somebody else has time to do it. But it's always kind of the soft option or the you know it's the thing that you do when you've ticked every other box…(FG.SP.DA)*

Some lived experience participants also opined that some of the service providers that they engaged with did not value their views, and as such were unlikely to see the importance of involvement processes. This is illustrated by the following quote from a mental health lived experience participant who felt that a consultant psychiatrist in his area strongly rejected the notion that the services his team provided could be improved by the voices of clients:

> *You'd have to challenge the doctor. This particular doctor, on his arrogance, because he is an arrogant man, and his theory is that 'If I don't think of it, it's not going to be used.' That's my view of him now, you know what I mean? If he doesn't come up with the idea, it's not going to be used. It has to be his idea… I don't know whether he would see us as being fit to talk to him…*(FG.PWLE.MH.SE)

Such experiences echoed findings from the national stakeholder interviews and service provider focus group discussions, where involvement – or indeed the prospect of change arising from service involvement – was thought by participants to be perceived as a threat by some, challenging the traditional service-provider/public and patient power dynamic. In some cases, the role of professions was highlighted in the resistance to service involvement with these groups, whether this was again clinical roles, or managers:

> *It's not simple, there are tensions and challenges and all of that. But I think it's maturing. So, there's a kind of a tension there always, I guess, with professionals in terms of who knows more and who has the authority to say what should happen, etcetera…And we saw it in terms of peer support, hugely… you know, some of the professions were hugely threatened at having peer support workers. But in fact, over time, those services are much, much better. And people realised it in hindsight, but at the time, it's a big hurdle for the professionals to let go of things… (SH.IN.06)*

Others national stakeholders noted that there still remained a need to emphasise the importance of engagement, and its potential positive impacts on different aspects of service delivery:

> Other barriers I suppose would be maybe our staff mightn't be aware, and managers included in this as well, of the benefits of service user involvement, you know… Whereas maybe identifying what the benefits to the organisation as well as the individual clinician or member of staff is very important. (SH.IN.01)

A number of national stakeholders and providers felt that assumptions were too often made around the capacities and agendas of those with lived experience. For some national stakeholders, it was the fear of challenging questions or honest feedback, that appeared to drive service provider resistance:

> *...I think we have a lot of people working in the organisation who wouldn't come from a culture of engagement with service users still. Some people are committed to it, others are kind of afraid of it, actually. Sometimes people are fearful of the honesty that they can draw out and they struggle to hear that. Engagement, you have to be able to listen if you're going to engage with people... And that can be threatening for professionals...* (IN.SH.06)

Participants described how having strategies in place at the organisational level would ensure that involvement is not seen merely as a concept, but as something which requires action and consistent practice. A number of participants highlighted that it is not enough for service organisations or units to say they are in support of service involvement; they must actively work to ensure effective involvement is undertaken. One stakeholder interviewee discussed this in the context of needing to actively facilitate culture change through 'enablers':

> *But culture changes very slowly and it's not something that can be done you know, by producing a policy. I don't believe that just having a policy on service user involvement will change the culture necessarily. You know, it will take a lot more other enablers to do that. But we can certainly start, and I think the process has already started.* (IN.SH.05)

Echoing this, service provider focus group participants argued that there should be clear organisational involvement processes set out, with service involvement built into service plans. This is illustrated by the following quote from a service provider participant from the mental health sector, who felt that too often involvement is relegated, restricted, or ring-fenced into a small number of activities and that this can result in missed opportunities. Instead, she felt service involvement should be an integral part of all work practices:

> *And I think when we bring it down to that reduced level of committees or peer support workers, we're missing out on I think, what I hear (other focus group participant) saying which is where is it systematically built into every layer and every aspect of what we do…we need to think about more models of how we're doing this and it's not just by sitting on the ops [operations] group…* (FG.SP.MH)

Similarly, service providers noted the ways in which engagement was often only assigned to a small team or an individual, with the implementation and success of any activities highly dependent on the commitment and actions of a few. The position of engagement activities within organisational work programmes was thus often precarious, and rarely sustainable:

> *So, you have the passion, you have the interest of a group of people, and they drive it...(but)...they move off* (to another job) *and it's not embedded* (FG.SP.MH)

6.2 Implementation and Action

Factors and concerns related to implementation and action emerged as a dominant theme within the research. Closely aligned with challenges related to leadership and commitment, this challenge emerged as a multifaceted set of issues, with several factors identified that enable or detract from the implementation of effective service involvement for the five populations.

At a base level, all informants in this research raised the lack of implementation of service involvement as a key challenge (also see 4.1). Many participants, particularly those with lived experience, felt that positive change in the delivery of care services – whether arising from service involvement processes or not – was either not happening at all, or not happening fast enough. Some participants described a simple implementation deficit where even if a particular policy has been introduced, there is often a failure to ensure the required plans and actions are executed. For national stakeholders who had been involved in coordinating significant health and social care programmes and supporting wider engagement strategies, there was a palpable sense of fatigue due to the lack of implementation. One stakeholder interviewee felt this was something which was endemic, and which had led those with lived experience to have a lack of confidence in service involvement processes:

> *…I think that that the lack of implementation, or I suppose slow implementation in some of those key areas…becomes a key challenge. Because if you have a number of consultative process, which are exhaustive and that have key recommendations for implementation, but don't happen. How do you ensure you know I suppose confidence in the system you know…*(IN.SH.08)

Service providers echoed these sentiments. Providers acknowledged the importance of implementation, as an integral part of their work but noted how those with lived experience are often disappointed with the (lack of) outcomes after involvement processes. This is illustrated by the following quote from a person who provides services to migrant, minority ethnic and Roma communities, wherein they note that meaningful engagement goes beyond only listening, to actual implementation:

> *The consultation process [in our project] was excellent. But what was delivered after, people were quite disappointed because they felt that their views weren't taken on board. And I think it's a real challenge at any point to jumble the people's wishes and how they see the perfect healthcare system, for example, was what [was] actually achievable to do... I think it's going to be very difficult to bring people for meaningful engagement…And then the other piece is that, just moving away from that consultation piece…that piece about beyond listening and consultation but at really adapting policy and programmes to meet the needs.* (FG.SP.MM)

For lived experience participants, the focus was on the lack of change. While participants pointed to micro-level examples of a lack of progress concerning their own care and the organisations they interact with, they again highlighted system level issues where they feel that those with the power to enact change based on their views do not do so as they fail to see the worth of their views. Some participants, therefore, framed service involvement outputs as simply something which is filed away with no further value, as the following quote, from an interviewee from a migrant background describes:

> *I think, I mean we have, and everybody else probably has the same idea – it's useful if they do something about it or with this information. If it's just data and in my time in a file, a paper file in a cabinet, that's no use at all.* (IN.PWLE.MM.07)

There were three sets of factors that were thought to drive challenges regarding implementation: insufficient or an absence of resources; deficiencies in measuring service involvement and establishing accountability for effective implementation; and inadequate follow-through in enacting changes arising from engagement activities. Each of these factors will now be discussed in detail.

6.2.1 Resources and training

In the main, all informant groups in this research highlighted the need for service involvement agendas and programmes to be supported by the provision of adequate resources. For many participants in this research, it was the absence of statutory supports that were the principal driver of implementation challenges. Without suitable resourcing it was felt that the effective mobilisation of involvement activities for the five population groups would not be possible in a meaningful manner. Adequate resourcing was deemed to be particularly critical by informants, especially service providers, who spoke about the need for more resource-intensive longer-term engagement activities to repair and strengthen relationships between the care system and some of these populations. This is illustrated by the following quote from a service provider working with migrant and minority ethnic communities who attributes a lack of progress in one specific form of involvement to under-resourcing:

> *I think and I know probably that [...] peer led services in the migrant space haven't been resourced appropriately. It hasn't been resourced appropriately and it's fallen behind.* (FG.SP.MM)

Findings from the service provider survey supports this view. Over two thirds of all respondents (69%) whose organisation engage in service involvement agreed that there is a lack of resources within the health and social care sector to support service involvement in general. There were much higher levels of agreement among those providing services to those with mental health challenges (77%) and to those from migrant, minority ethnic and Roma communities (94%). Just 14 per cent of respondents said that there had been adequate provision of resources to assist organisations in engaging the populations that they serve. While just 21 per cent of NGOs felt there were adequate resources, none of the respondents from Section 38 organisations agreed that resourcing was appropriate.

In terms of the types of resources necessary, the importance of programme budgets for the implementation of engagement was recognized as being essential and were spoken about by all study informants. In many instances, however, it was what these budgets enabled that was the main concern of participants. National stakeholders and provider participants were strongly focused on the need for human resources. As outlined in 6.1.2 with respect to buy-in, the majority of national stakeholders highlighted dedicated staff allocated to engagement activities for the five groups as being one of the most important resources:

> *So, [service involvement] needs to have dedicated staff. Now, [named hospital] is lovely. They have a…Patient Liaison Officer. You know?... [but]…we need two or three but that's beside the point. So, there's not enough emphasis nationally on having bodies on the ground to drive this.* (IN.SH.03)

It was suggested that the provision of dedicated staff would help avoid personnel within organisations being overburdened, and help drive and execute involvement agendas:

> *And the doing of good service user engagement takes time away from [routine service provision]. So, the challenge will be what doesn't get done...If your resources are finite, you're competing with the waiting list or the productivity. It's around how you have evidence that good service engagement is going to add value to the service because it's competing as a concept with other bits of the service.* (IN.SH.09)

However, just 42 per cent of provider survey respondents reported that their organisation had allocated personnel for managing or conducting involvement (although this may not be their sole focus within their role). The proportion of organisations with these roles were much lower amongst those serving migrant, minority ethnic and Roma communities (24%) and the Traveller population (25%). Although, 70 per cent of large organisations (more than 500 personnel) reported having dedicated engagement roles, only 22 per cent of medium (21-50 and 51-100 personnel) and 39 per cent of small organisations (fewer than 20 personnel) reported having these roles.

An adequate investment in training and development was similarly flagged as being critical in the effective implementation of service involvement for the five groups. National-level stakeholders and service providers noted that personnel need to be sufficiently trained to ensure that there is no staff resistance to engagement, to help minimize barriers between service providers and those with lived experience, and to help support the execution of engagements in an inclusive manner. Nonetheless, just 44 per cent of respondents in the service provider survey stated that their organisation facilitated training on service involvement. While this proportion varied considerably with organisation type (66 per cent of NGOs facilitated training; 89 per cent of Section 38 organisations facilitated training), it was generally asserted that attempting to encourage the uptake of training amongst a workforce who are already stretched with workloads is a significant challenge. As one national stakeholder suggested, training and development must not only be concise and fit with intense working schedules of staff members but must be framed as a means to achieve more effective working:

> *Like staff who work in healthcare are extremely time poor, especially those who work at the frontline. So, we realised that very early on in our programme. So, if you want to sell something to them and that's a, you know, a good way of working, you have to identify for them how it's going to save them time.* (IN.SH.01)

Resources were also discussed in relation to the payment and renumeration of those with lived experience (other forms of support required by those with lived experience are covered in section 6.3). Although a number of national stakeholders argued that some of those with lived experience may have no desire to be financially compensated for their contributions, they should have costs and out-of-pocket expenses associated with participation reimbursed. Other interviewees argued that it is only fair to pay people for their input, especially if they are required to make substantive contributions. A small number of service provider focus group participants discussed how insufficient remuneration, or tokenistic forms of appreciation, for involvement can prevent people from taking part. This person from homeless services highlights the prevalence and problematic nature of such weak gratitude:

> *I was at the [specific homeless] conference the other day… there was a discussion, and it was around peer involvement, and one of the things they said at it was 'Payment, not pizzas' and it just like, was like 'Yeah.' I mean how many times were you like 'Let's have a pizza night, and that'll get people involved and stuff'?… and she was from the US, and it just made me kind of smirk to myself, as like it's obviously international. Pizzas are like the currency of choice.* (FG.SP.HO)

For lived experience participants, the focus was again on the perception of how their input was being valued. In responding to a question on what would help or hinder involvement, one lived experience participant speaks about his own experience of engagement and the need for remuneration when there are very real costs in time and money incurred:

> *Probably money…I do a free service on a Thursday night on Zoom for [named treatment centre]. I do a speaker talk and it's no charity. I enjoy doing it and get a great benefit from it but there's time you're going down there and you're on your own diesel and you're driving down as well and you're just thinking, 'Fuck's sake', you know, selfishly enough. I shouldn't be thinking like that but I'm a human…*(IN.PWLE.DA.02)

A number of service provider participants spoke about the importance of this valuation and how payment helped to frame those with lived experience as partners in the service involvement process, equal to those service-providers in attendance whose time and experience are being financially rewarded. This view is illustrated by the following quote from a service provider in the mental health sector speaking about peer-workers:

> *...it's levelling the playing field for people. It's getting service-users, paying them to engage you know, paying them for their time to turn up at meetings that professionals are being paid to turn up at already, you know…* (FG.SP.MH)

6.2.2 Measurement and accountability

Many of those involved in this research stated that successful implementation of service involvement must be driven by evidence of effectiveness. A number of national stakeholders spoke about the need to demonstrate how service involvement generated improvements in service experiences and outcomes and how, as described by this interviewee, this needs to be embedded into how implementation is judged:

> *... so engagement feels like the right thing to, it makes us all feel warm for doing it. But really, in terms of delivery of services, what has it done? So, has it actually improved satisfaction? Has it actually improved the quality of the service? Has it reduced incidents?...we do have to measure it as we go because it can be quite a big investment, both in terms of time and financially, and we have to know that it's making a difference.* (IN.SH.06)

Some study informants described how key performance indicators (KPI) should be established as a means of supporting this assessment and in fostering a culture of accountability. Without these two factors, it was felt that service involvement would not be truly prioritized as a sector wide-agenda and an organisational objective. But participants, particularly service providers and stakeholders, emphasized that there was not only an absence of standardized indicators, but questions around what should be measured. National stakeholders and service-provider focus group participants discussed what would indicate ‘good’ or ‘bad’ service involvement. Some of these participants noted the need for robust quantitative indicators, for example the number of engagement activities organised, or the number of people involved. However, in line with the goals of involvement presented in Chapter 5, it was generally suggested that a wider set of measures was necessary, and that these measures should be supplemented with more in-depth qualitative assessments where appropriate. This would include hearing the views of those involved on the process of involvement and, as this provider from a drug and alcohol service outlines, the outcomes of involvement:

> *...I think it’s [effectiveness measures] sometimes often about the numbers and about the stats… and you know the things that can constructively be seen on a screen from a HSE building or whatever it is. But also, it’s actually about [if] this person feels very differently...esteem, confidence, you know other things that are harder to...state whether there's been a shift. I think sometimes that’s more useful for the client, although the funders want the stats...* (FG.SP.DA)

Nonetheless, and regardless of the specific measures, one stakeholder and some service-provider participants discussed how indicators of effectiveness should be utilized to reinforce a culture of accountability with respect to the implementation of meaningful involvement programmes. This was also suggested as a potential basis for resource allocation and for awarding high performing and effective engagement programmes.

Despite strong consensus among national stakeholders and service providers on the need for comprehensive, effective measurement of involvement activities, measurement was not thought to be widespread. This view contrasted with the findings of the service provider survey which indicated that assessment of involvement activities was more frequent. However, almost a third of respondents (32%) reported that their organisations did not conduct evaluations of its service involvement activities.

6.2.3 Follow-through actions arising from service involvement

Closely linked to measurement and accountability, the importance of follow-through action and generating impact arising from service involvement activities was highlighted by the vast majority of study informants. Thus, it was not just implementation of involvement programmes that was deemed to be important, but the implementation of action that those activities call for, such as service reforms and new service development. This is in line with the general consensus presented in Chapter 5 that service involvement should strive to achieve improvements in service, health and inclusion outcomes for the five populations. However, many stakeholder interviewees and service-provider focus group participants agreed that involvement was often beset by a lack of follow through. It was this absence of action that served as one of the biggest challenges facing the longer-term implementation of service involvement. One national stakeholder noted that this may be a problem which is particularly acute in the Irish context:

> *...in Ireland we’re better at setting policies than implementing then. That’s a bit of a, an actual weakness we have in Ireland. Our things are piloted, and the pilot isn’t extended even if it works well.* (IN.SH.02)

Service-provider focus group participants described how if those with lived experience do not see actions arising from their participation, they may not get involved again. Survey results also suggested that a lack of follow through was an issue amongst service provider respondents, with over a third of respondents (38%) indicating that there was not a clear pathway for harnessing and communicating results of service involvement within their organisation. This was notably higher for those providing mental health services with two-thirds of these respondents reporting this challenge. It was suggested by one national stakeholder that this issue might be more prevalent in HSE services due to the large scale of the organisation and the difficulty of applying changes consistently. Without implementation of involvement recommendations, one interviewee argued these processes can be merely 'tick box' exercises:

> *I could say: 'These are my key issues' and you say, 'Great that's fine, we'll do something about it'. And nothing happens, you know so you've ticked your box. You've said you've consulted. You've engaged with me. You've you know addressed my concerns in terms of service user involvement. But actually, what's been the follow up?* (IN.SH.08)

Similarly, lived experience participants highlighted that the lack of follow through means that people can become disillusioned, and as a result their confidence and trust in service involvement systems can often be lost. Indeed, many of these participants believed service involvement activities frequently have no impact with output documents getting '*…ripped up and thrown in the bin'* (FG.PWLE.DA.OO). For some populations, such as those from the Traveller community or those who use mental health services, people pointed to a long-standing history of consultation and information-gathering, with no obvious change. In these cases, lived experience participants described how there often is a good knowledge of what the problems are, but no actions are taken. For some, and as illustrated by this exchange between Traveller focus group participants, lack of action can translate into a real sense of frustration:

> *P1: ... we have done this kind of [thing] over and over and over…*
> *P3: And there's a lot of the stuff yeah but there's been research since that that has shown the same barriers, the same causes, same triggers… What I'm getting at is, is there a need to swing this research completely around on the services and say, 'What are ye doing and what are ye not doing?'…like we're the most over-researched group of people and I'm sick of it.* (FG.PWLE.TR.DU)

Correspondingly, national stakeholders argued that service providers can also become frustrated when they are not empowered to make changes based on this feedback. Interviewees emphasised the importance of facilitating service providers as much as possible to be able to implement recommendations arising from service involvement engagements. This could be done through: the provision of guidance documents; by making clear how such guidance fits with existing frameworks; by building on any work which has already been done in this area; and finally, this can be facilitated through the provision of suitable resources.

6.3 Population Capacities

It was generally recognized by all sets of study informants within this research that the capacities of the five diverse populations needed specific consideration, and to be appropriately accounted for, harnessed and empowered within the development and roll-out of service involvement programmes. Capacities in this context does not refer to individual level abilities, but instead emerged as multidimensional in form and referred to psychological and cognitive states, perceptions of self, and someone's personal acquired knowledge. All informant groups felt that the need to consider population capacities was especially important for the five populations, due to individual and group-level life-course circumstances. However, it is important to note that study informants also recognised that those who had experienced marginalization, as was evident amongst many of those in the five groups, could bring considerable strengths to service involvement, whether arising naturally or through an accumulated resilience to adverse circumstances. The findings that will be presented within this section point to the need for a capacity building approach in service involvement that attends to the potential of individuals and groups across three key dimensions: psychological readiness; confidence and self-esteem; and understandings of service involvement.

6.3.1 Psychological readiness

It was evident that the psychological readiness of members of the five groups must be considered in service involvement activities. Lived experience participants in both focus groups and interviews argued that many people in the study's population groups may not be in the right psychological space to participate in service involvement processes. This was recognised across all informant groups. For example, 55 per cent of survey respondents agreed to a moderate or large extent that precarious living circumstances and social exclusion among those who use services was a challenge that can disrupt service involvement activities. Those providing services to migrant and Traveller communities were much more likely to agree that exclusion impacted their user groups engagement, with 94 per cent and 88 per cent of respondents respectively agreeing. Within this topic, four key factors were identifiable from participants' narratives and responses.

First, people spoke about journeys to regain stability or control in their lives – whether after a period of drug and alcohol use, mental health challenges, homelessness or other factors that impacted their psychological well-being. Therefore, while there may be a desire to contribute to services, some acknowledged that they may not feel ready to take part. For some participants this was due to not feeling psychological well enough or not having the cognitive space within their lives to take part. Others described how they felt that they did not have enough time to reflect on their experiences and needed to concentrate on their own wellbeing and/or recovery. The following quote from a woman who had been homeless, and who was in drug and alcohol recovery, illustrates this view:

> *If you asked me, I wouldn't get involved anyway, because…at the moment now, I wouldn't be ready to talk to other people. I wouldn't be able to give advice to help people or help me change anything, because I'm just changing myself. I'm only getting a grip on my own life at the moment, so I wouldn't be able to help anybody at the moment. In the future, probably…But I wouldn't get involved, if they asked me to be involved, to be in the group, to do something, I wouldn't be able to, at the moment.* (FG.PWLE.HO.RS)

Second, several lived experience participants spoke about how trauma and accumulated exclusions can function to prevent and dissuade people from participating. For some individuals it was clear that issues around personal stability, trusting others, stress and anxiety and material and social deprivation intertwined to create very real obstacles to getting involved. Other participants emphasised how the accumulation of traumas and exclusion led people to erect psychological barriers, which they used to keep people at a distance. As one man succinctly describes about the barriers he created: '*…they won't let you in…*' (FG.PWLE.HO.RS).

Third, study informants described how many members of the five populations can face complex health issues, which can combine to affect a person's ability to contribute, particularly in a group setting. For example, 73 per cent of provider survey respondents cited the complex health needs and conditions of those who use their services as a challenge in engaging these groups. The following quote from a male interviewee who had previously experienced difficulties with depression, reflected on how the health capacities of his peers impacted their engagement in a service involvement workshop:

> *Now, I found that, maybe I was in a better state of mind than even the people that were there like. They went alright, but they didn't contribute, a lot of them. They didn't contribute…I would have thought that in part they weren't kind of still well enough, you know…They were still suffering from the effects of depression…* (IN.PWLE.MH.04)

Another male lived experience participant spoke about the intersection of drug use and mental health challenges and the reality of dealing with these issues in daily life. As he describes in this quote, such situations bring into sharp focus how some people in these kinds of populations can find involvement activities psychologically challenging and potentially distressing:

> *….there's an awful lot of psychiatric problems, there's an awful lot of mental goes with the drugs. You know, you wake up full of… you know the anxiety!…. Well it's a horrible thing for an addict, you know? They'd be actually quite sick in the mornings. Yeah. When they could have the runs with it and all. That your whole insides is like a bunch of butterflies, and you're so nervous. And you're not afraid of anybody in particular, but yet there's an inside fear, you know, that needs to be sorted out before you can start to think [about talking to anyone] one-on-one.* (FG.PWLE.DA.OO)

Fourth, and in the context of these first three factors, a number of people described the difficulties in managing multiple demands in their lives. These demands can exacerbate feelings of stress serving as a barrier to service use, not to mention service involvement. Demands can be more challenging for individuals from marginalised populations, given that they may have fewer social supports, and subject to greater and multiple vulnerabilities. In discussing his capacity to meaningfully contribute to service involvement processes, one focus group participant said:

> *…I'm minding me Ma the last six weeks and it's hard work. But I'm working tomorrow and Sunday, and I know tomorrow I'm going to wake up and I'm going to be even more sicker, so I'm thinking… I'm sitting here listening to you, but I'm also thinking of how I'm going to get my fucking gear like…That's being honest. (FG.PWLE.DA.OO)*

In contrast to issues around psychological readiness, lived experience participants who were in a good place psychologically felt that they had the capacity to contribute. Many participants, especially those on recovery journeys, appeared to be particularly grateful to some services and individual service-providers, and were eager to help others who are in similar situations to theirs. These individuals described how the notion of 'service' is a fundamental element of many recovery programmes, and how 'giving back' can be empowering for those who have come through adverse circumstances. These ideas were explained by one participant from a focus group with those who use drug and alcohol services:

> *Because I think once you kind of get sober, and I think that's why sponsorship is so big in AA, you get to a certain level and then it's this feeling of being able to give back and that gives you… it empowers you to be able to help somebody else. And I think something like that, like one of the first things when I had my first kind of period of sobriety…I was like how do I… how like, what can I do to help, like how can I get involved? Like is there something I can be doing.* (FG.PWLE.DA.CD)

Some lived experience interviewees and service-provider focus group participants, however, thought that there would be some individuals who would be hesitant to 'go back' to a supporting service or recovery environment even if their own circumstances had improved. One service provider in the homeless sector understood this as relating to a desire to put negative experiences behind them, focusing solely on the future:

> *You know, it's all case based, and some people work really well within the system, and go on to feel empowered from being… having had a period in supported services. And other people who just want to leave it behind, it was kind of a shameful time in their life, and but they've got through it now and they want to get on with their lives.* (FG.SP.HO)

6.3.2 Confidence and self-esteem

Several lived experience participants discussed how they or their peers may place little faith or value on their own opinions and views in relation to services or may believe that they would not be the most appropriate candidate to participate in involvement activities. For some, this was related to not feeling 'qualified' to take part. An interviewee who had used drug and alcohol services described this in relation to more general experiences of service use, where similar feelings and concerns could arise:

> *Well I find when you engage with a service, a lot of people in heavy [drug] use would have very low self-confidence and turning up to a place and don't know anyone's name or any structure for it, they could run for the hills if they get a bad feel of it.* (IN.PWLE.DA.05)

Some lived experience participants described how they would feel especially nervous to engage with those who they perceived to be in positions of power relative to theirs, for example doctors or other professionals. This is illustrated by the following exchange between two participants in the focus group discussion with people with experiences of rough sleeping:

> *P1: Well, I would imagine going into a group like this… people from lots of different backgrounds. And I would know personally myself, you'd have a little bit of a question mark about where people are coming from, and a little bit of maybe confidence and anxiety issues.*
>
> *P2: …if they're more important than you, like. Are you only (an) addict, where's their*

> *background, where are they from. Are they coming from wherever, college of… you know what I mean, top dog, and you're just walking in like, off the street kind of thing.* (FG.PWLE.HO.RS)

Furthermore, the use of technical language or jargon was cited as a factor in triggering feelings of inadequacy. As such, some lived experience participants felt such situations should be avoided where possible. One Traveller interviewee discussed his own experiences of public workshops in this context, describing his own dislike and that of other members' from the Traveller community for this form of involvement:

> *There's a lot of information and there's a lot of big words and there's a lot of words we don't understand. There's a lot of information we have to take in and then there's a lot of reading in it, and a lot of us are not confident in those areas…that's why Travellers don't get involved in these things…Too much information, too much words used that we don't understand.* (IN.PWLE.TR.02)

Many others mentioned having a general low level of self-esteem or confidence, which was often attributed to their situations, for example being displaced, being in recovery, experiencing homelessness, or experiencing depression. A participant who experienced homelessness stated:

> *I don't know. Like I probably find that in group kind of settings like that, I'd be quite intimidated or I feel I go a little bit, because I'm insecure, I go a little bit in on myself And whatever I've to contribute is stupid or not good enough or it's wrong or you know. There could be strong personalities in the room and I tend to go quite withdrawn. (IN.PWLE.HO.7)*

To overcome these barriers, it was suggested that boosting a participant's confidence and lessening feelings of intimidation was essential. As outlined by this service provider supporting the Traveller community, helping lived experience participants to understand their right to have a voice and that their voice is at least equal, if not more relevant in involvement processes:

> *So, there is a need really to I suppose support that work more and to provide I suppose better… more an understanding of why their voice is of equal if not more importance at those meetings and for them to feel confident and have the confidence to participate fully in those settings I think is really, really important.* (FG.SP.TR)

It was argued that providing learning opportunities, or training, would allow those with lived experience to advocate for themselves and others. This was seen as being fundamental because of how disempowered some members of the five populations can be. A participant in the focus group with homeless service providers explained the practical and psychological context within which many people who experience homelessness exist, whereby having no say is normal. This, she argues, makes it difficult when suddenly being asked to express their views:

> *...we're working with people that there's a whole history where they had no control and they had no involvement and they were told what to do and their voice was never heard...(so) they might be working from a completely different perspective, so that*

> *whole involvement can be quite difficult and can get really quite complex to manage...*(FG.SP.HO)

Lived experience participants argued that it may also be appropriate to facilitate family and/or community and key workers in supporting participants during involvement processes, whether that is to provide moral or instrumental support. This will allow service involvement participants to feel more comfortable and confident, and thus provide a better position from which to make meaningful contributions.

It is important to note, however, that a number of lived experience participants in this study – most of whom had a long history of being engaged with services –were adamant that they were not intimidated by those who they encountered in service use, or in service involvement. These participants spoke about how they understood that everyone is equal, regardless of origins, level of education or current situation, and because they understood the value of their experiential knowledge.

6.3.3 Understandings of 'service involvement'

Understandings and familiarity with service involvement was an important factor in determining lived experience participants' capacity for engagement and was connected to the previous challenges around confidence and self-esteem, Fifty-three per cent of service provider survey respondents reported that there is a lack of clarity in understanding regarding the meaning of service involvement and its different methods. Both in interviews and focus group discussions, lived experience participants argued that a lack of familiarity with service involvement and its key processes may mean that some individuals would be reluctant or technically under-prepared to take part in engagement activities. Participants described how these individuals may not know what to expect, and what opportunities for engagement are available. As this lived experience participant from the Traveller community describes, these circumstances can generate more superficial forms of engagement:

> *[Training is]…very important because…getting Travellers into the room and they didn't even know what they were in the room for. It's a hundred Travellers sitting there nodding their head. We're not a believer of that. We're believing in real participation, real decision making.* (FG.PLWE.TR.DO)

To counteract this, people contributing to this study asserted that participants should be provided with training or should be at the very least well briefed on involvement processes in which they have been invited to participate. Study informants described how lived experience participants in any form of involvement need to understand their roles and responsibilities, as well as the function of the engagement processes that they are participating within. Some service providers described how training might also give lived experience participants specific skills such as how to do a presentation, how to deal with conflict, or to utilise certain technical or specialist language. Stakeholder interviewees argued that training was the most important aspect of capacity-building and should be an inherent part of any service involvement model which aims for meaningful engagement. At the same time, some providers felt that these forms of supports can be too time intensive, under current resource constraints, with the need for such preparation sometimes used to rationalise why lived experience perspectives were not integrated into some services:

> *... we would have people in recovery on our board, but we don't have a specifically designated service user...because...there needs to be a lot of kinds of proprietary work*

> *done, there needs to be a lot of mentoring done, there needs to be a lot of development done with the service-user to...bring them to that space....* (FG.SP.DA)

Findings from discussions with lived experience participants point to the need to engage with different participants in different ways, according to their capacities, but also according to their circumstances and preferences. Approaches to engagement which are flexible will allow larger numbers of service-users to be involved in ‘shallower’ engagements, and a smaller number, perhaps those with greater capacity to accept a higher level of responsibility, to be involved at a deeper more intensive level. Some lived experience participants stated that the best way to establish participant preferences for participation is to simply ask them.

6.4 Trust

Informants across all research strands noted that trust and respect were key challenges upon which the success of service involvement with the five populations often hinged. For the most part the emphasis placed on these factors related to the entrenched, intersectional exclusions that the populations (or some of their sub-groups) may face, and which are considered to undermine the ties of individuals and groups to the health and social care system, and society as a whole. More than half of service provider respondents (53%) felt that members of these populations were less likely to have confidence in involvement processes. It was generally noted that a substantial investment in trust building is required to respond to the negative experiences that some members of these groups may have had in health and social care services and in wider society. Four different dimensions of this challenge were evident in the research: trust (or lack thereof) in structure and systems; trust in relationships; fear and personal or psychological safety; and rights to privacy and care.

6.4.1 Structures and systems

Service-provider focus group participants, as well as a number of lived experience participants, highlighted that there can be a lack of trust in the state, in services generally and in the HSE specifically. First, and in terms of service involvement, those who use services can be slow to trust that their participation in involvement is anything more than tokenism, with state institutions perceived to be slow or resistant to change. As explained by one Traveller interviewee, this again relates to the perceived lack of follow through discussed with respect to harnessing service involvement outputs to drive improvements and change:

> *… if I’m to be honest, we feel, as a Traveller culture sometimes, […] what is the point? Because sometimes, it’s going to be ran the same way. People want to know our opinions and they want to do surveys and they want to understand us, and they want to make services better for Travellers. And then Travellers don’t see the outcome of, well how come we’re losing so many [deaths due to suicide]. So what’s the point, you know. So it’s like you come look for us and want to have a look into our lives and look at our culture and how do we make ye make us better by coming in, but we don’t see that.* (IN.PWLE.TR.02)

Second, a lack of trust can be driven by real and perceived power imbalances. A number of national-level stakeholders and service providers described how marginalized populations can perceive themselves as being less powerful than service-providers, leading to a social divide due to this perceived hierarchy. This was particularly evident amongst migrant and Traveller groups, because of historically poor treatment at an institutional level. The views of many migrant participants appeared to be coloured by their experiences with state institutions, or political-economic systems in their countries of origin. As this Roma participant outlines, the legacy of this form of treatment can be cognitively transferred from home country nations to Ireland, with subsequent implications for trust in the Irish system.

> *It's very important to mention that when you have marginalised Roma community come in from Romania, Slovakia, and they come in from very bad conditions from Slovakia even into Ireland. It's a totally new system for them. And it's about building the trust between the health centre. It's the most important thing for them to understand that they can trust the HSE, that they're trying to help them. So, building the trust between the HSE and especially the marginalised Roma community is very important as well.* (FG.PLWE.MM.RO)

The outcome of such mistrust is less than optimal engagement with such agencies. The following quote from a Chilean migrant illustrates how growing up during and in the years following a decades-long dictatorship led to a cynical view of institutions, and the sense of having no control:

> *I got to a point that's I don't even question the system anymore…That's why I don't stress myself with anything. What is going to be, is going to be. So I always think things like that, yeah, on paper it works but then, delegation, they don't make it work…I have two very, very important experience in Chile that plant a seed on me of that I don't believe in the system and I don't believe, in general, in people but people as a big group.* (IN.PWLE.MM.07)

Service-provider focus group participants noted that this mistrust in systems also emerged from the disrespect shown towards some or all of the five groups. Many providers within the focus group discussions spoke about how respect for those who use services should be present in every interaction. This was considered to be even more important given that some participants believed that they are so often not treated with dignity and respect (also see below).

6.4.2 Relationships

It was clear that there can also be a lack of trust in individuals and in the interpersonal relationships within these systems. A number of lived experience participants in this research questioned the values of some professionals working in health and social care. The following quote from someone who had used drug and alcohol services was distrustful of the motivations of certain actors and support workers in that space:

> *They'll turn around and they'll say they'll listen to us. They hear us, but they're not fucking listening. You know? They're not doing anything… they're in it for the money. Or they're in it for a promotion to get more money, so they are.* (FG.PWLE.DA.OO)

While professional/occupational roles were often the key focus of challenges around mistrust, it was clear that a small number of lived experience participants felt the issues could be broader. This person, who had experiences of homelessness, describes their strong views on the nature of some of the keyworkers and lived experienced workers that they have come into contact with, and the sort of ethos to which they seemed to prescribe:

> *Them keyworkers that are being employed are some of the nastiest bolloxes I've met… failed boxers that realised they're not going to be Rocky, and they go off and do a few drugs and then they get saved by Jesus and they want to give back…I've seen them power tripping…egotistical bastards, and not just one or two of them. I've seen some of the nastiest bastards in this business. I really have and they sicken me. And then they get these peer workers, closet coke heads, and they just think they're so above because they went to [treatment centre] or they went to that brainwashing shithole, [another treatment centre].* IN.PWLE.HO.05

Building relationships and trust takes time, not just due to depth of previous negative experience amongst some individuals but also because of what is required of them in these relationships. Many lived experience participants described how it appeared that they have to continually open up and ask for help in relation to very serious and upsetting situations, intensifying their sense of vulnerability. However, this vulnerability can often be exacerbated by staff turnover, and the need for those with lived experience to re-tell their story again and again to people who they may not yet have trust in. For many participants in this research, these experiences were very stressful, as this female focus group participant who was experiencing homelessness explained:

> *…She was my keyworker... But I really, really trusted her, you know? I had big trust in her. And then when she left, they were trying to assign all these different keyworkers to me and I was like, I'm going with someone that I feel like I can trust. And I found one, do you know what I mean? But it was hard, like, to get trust back with them, like. Do you know what I mean? And like… When you open up to someone then you have to open up to another person, then you have to open up to another person. Then when you move out of that place, you've to open up to five more people. Do you know, like?* (FG.PWLE.HO.SA)

It is in this light that many lived experience participants raised concerns regarding being able to participate in service involvement. Building trust in this regard as a part of the involvement process was considered key. This related first to giving time to build relationships between participants and key facilitators who can help explain the process and make reassurances. A number of participants stated that they would only engage in service involvement processes if they had a relationship with those professionals who would be involved:

> *…if I know who is there, whom I'm to speak, you know, whom I'm going to meet, whom I'm going to speak, you know…So I will definitely go, if I am aware of that person, if I know who are…I would prefer if I know whom I'm going to see, yeah, beforehand.* (IN.PWLE.MM.05)

Building trust also related to setting time aside for fostering connections and relationships between all the participants within a multi-person process:

> *I think maybe if prior to those kind of workshops or whatever, like have things that you can, I don't know, like icebreakers or going for a breakfast or a little coffee or something. I don't know, so you can get to know and sort of build that kind of trust and kind of feel comfortable already to create that safe space maybe, to help that. And maybe having a supervisor or somebody who's overlooking this all happening so things don't get out of context if that makes any sense?* (IN.PWLE.HO.07)

Finally, some participants, mainly service providers, reasoned that it may be useful to build trust through community groups or brokers, with whom people with lived experience have created relationships with over time. This view was especially strong among Traveller participants, as illustrated by the following quote from a service provider who describes experiences of involvement processes failing when not organized through Traveller Health Units or through Traveller peer research, where trust has been established with the local Traveller community:

> *... I suppose, you know, the current level of engagement we'd find at primary healthcare project level and Traveller health unit level, it's quite good. And if the Traveller health unit are leading a group or trying to get Traveller engagement, I suppose there's a connection and a level of trust there, so it's probably easier to get Traveller engagement. I think if we're asking Travellers or if their project is being requested for a Traveller rep to engage maybe with a broader service, I think that's where it can be more difficult for the engagement to happen…* (FG.SP.TR)

6.4.3 Privacy concerns and impact on care

Lived experience interviewees and focus group participants raised concerns about confidentiality and how the information they contribute would be used in involvement processes. These issues were often a symptom of the mistrust in the broader health and social care system and/or mistrust within interpersonal exchanges presented in the two previous sections. Participants were concerned that sensitive information about their experiences might be divulged. While some lived experience participants acknowledged that sensitive information was often provided within a health and social care setting, this was usually under strong privacy protections and/or helped to aid their access to much needed services. Some participants felt that the cost of exposing private issues in involvement processes may not be sufficiently justified given the more modest benefits of involvement.

However, a greater concern for individuals with lived experience was that being openly critical of a specific care service might negatively impede access to these services in the future. This service provider in the homeless sector outlines how a lack of confidence in providing feedback amongst users of services is often a function of having to engage with someone who has control of the services they receive:

> *…you know, their confidence has been broken down, their self-esteem, so knowing to be able to talk up for themselves, or say 'Look, there's something not right here' it can take a lot of confidence to say that to somebody who's ultimately making a decision over whether you're staying in the service or not as well. You know the… any of the women that stay in (named temporary accommodation venue), they have to go to a local authority to have that approval, so it's that power and control element does impact individuals.* (FG.SP.HO)

In other cases, it was clear that some members of the population groups in this study felt that their trust in service involvement processes was betrayed, with information around the purpose of engagement not being made sufficiently clear. This quote from a female lived-experience participant illustrates these concerns and the damaging consequences that such experiences have not just for a sense of trust, but personal well-being:

> *They asked me to do an interview with [organisation name], right? I was like, what's it for? Oh, a newsletter. Then I found out it's for the accounts or something?*

> *Accounting or the way the things work and… The lady printed out everything I said and I was high that day as well…. And then it was printed and I was like, fuck. The manager came and gave it to me and she was like: 'Do you want to sign it?' I was like, I thought this was anonymous. And she was like: 'Well, it's only for…' I said, 'What is this for? Why are people lying to me?' And I was getting really paranoid and she was like… I didn't say anything too bad but I didn't say anything great either about the place… I don't even think I still got the truth because she said it was about like, an audit… OK? And I was like, why am I being asked about a goddamn audit? ... And then the woman, it was via Zoom as well, and she was asking me like, how I ended up there. And that was really personal, like. And it was printed down. Like, I felt like this was five months after I was in there and I just felt really betrayed and it was just more and more shit I guess and then I just… You know? I just lost it. I didn't even get up anymore. I was like, what's the point of even showering. I don't even care about this.* (FG.PWLE.HO.SH)

To overcome concerns around privacy, lived experience interviewees felt that facilitators of engagement activities should make goals of involvement processes and what participation involves very clear. Both lived experience informants, providers and national stakeholders felt those taking part in service involvement should be assured that input, however critical, will not impact on their access to services, or the quality of care they receive. This should be done in advance, to help recruitment, and on the day to maximise participation.

6.4.4 Fear and safety

Service-provider focus group participants and lived experience interviewees highlighted how difficult, and even scary, it can be for people who have experienced entrenched exclusion to speak up, particularly in the company of health care professionals. It was clear that trust barriers did not only stem from systems and relations, but also arose from significant life traumas and long-standing marginalisation's that gave rise to fear of threats to personal safety. For some individuals, these fears were based on experiences of harm, with the following quote, from a woman who had experienced human trafficking and sexual exploitation, illustrating this dynamic.

> *I'm struggling mentally really. My self-confidence is gone, I don't have it at all. I don't trust men. Even if a man looks at me, I don't think that's a single girl he may like, I'm just thinking everything what's happening to me is written all over me or that's what he wants to do.* (IN.PWLE.MM.06)

While these experience-based trust issues were viewed as a significant challenge when attempting to engage with people in these circumstances, study informants (including service providers and national stakeholders) noted that it was imperative that involvement offered a safe supportive space for these individuals and groups. The following quote from a Traveller interviewee illustrates that when such a space is not created, traumatic experiences, in this case racist discrimination, can re-surface and have long-lasting traumatic effects:

> *No, I didn't like that there was a big group looking into my face and I was the only Traveller sitting in the room. I felt mortified. I felt ashamed. I felt like I wasn't myself, I didn't know how to talk. I felt like there's too many settled [people] – I know it sounds wrong – but there's too many settled people here. God knows, they'll all be chatting and yapping about, 'Look at that Traveller going out there, badly depressed,*

> *and the other one', and I know they probably wouldn't because they're a great organisation and I wouldn't ever say they would do that and I'd always hold my hands up. But it's always at the back of your mind, and I know that sounds terrible, but because you've been discluded your whole life, it's your instinct of thought, 'Am I being talked about? That's a knacker', blah, blah, blah and like I said, it's a terrible, terrible thing to be even thinking when you're walking out the doors of an organisation or a support organisation or whatever it may be. It's a terrible aspect to be thinking but like I said, when that input is put on you from an early age and you've been growing up with it your whole life and you know no different than anything else…*(IN.PWLE.TR.05)

6.5 Representation, Stigma and Discrimination

Descriptions of challenges related to representation, stigma and discrimination emerged strongly within the research, with prevalence and implications highlighted by each set of study informants. In some instances, participants were able to highlight aspects of service involvement, or even services, that helped to avoid or respond to such challenges. However, generally study informants more frequently spoke about specific challenges that needed to be addressed within involvement. For those with lived experience, participants drew primarily on past experiences of services to highlight their concerns and cautions with respect to how representation, stigma and discrimination may feature within involvement itself. In other cases, these experiences were raised as perhaps being representative of a broader system feature that could detract from the capacity of service involvement to affect positive change. It was also clear that challenges regarding representation, stigma and discrimination were core drivers of the mistrust in the care system in section 6.4. These challenges were, for some individuals in some of the groups, interrelated and connected across a spectrum of experiences.

6.5.1 Representation

Reflecting the goal expressed by lived experience participants to represent a diversity of perspectives within involvement activities (presented in Chapter 5), representation was a key concern for some of the population groups, as well as national stakeholders and providers.

First, this concern related to the need to represent the population groups due to a traditional lack of inclusion in involvement processes, recognising that the marginalisation that these groups can encounter can extend into the realm of involvement. Where engagement processes are focused on the voices of the population generally, some lived experience participants and national stakeholders argued that those included tended to be characteristically homogeneous or 'mainstream' people. This is highlighted by a focus group participant who notes the design of engagement activities was not conducive to representation:

> *You know, no disrespect to surveys like this, you'll get the white, settled person answering them. That's who normally answers them…you'll get the same kind of people having the time to do that and the ability to do that. There's challenges…If that form was sent out to my mother-in-law or any members of the family that couldn't read and write and they're not really understanding what it is, they wouldn't do it. That's just reality.* (FG.PWLE.TR.DO)

While over half of the respondents in the service provider survey (51%) reported difficulties in recruiting and retaining an appropriate sample (diverse, inclusive) of members of the five populations, a national stakeholder succinctly described how problematic it is to only have ‘the usual suspects’ taking part:

> *I see the same faces popping up all the time. And I’m not too sure how representative that is anymore. I think…we need to challenge ourselves to actually engage with different groups.* (IN.SH.06)

A second and a more dominant concern around representation related to being able to reflect the diversity of individuals and sub-groups within the five populations. In this regard, informants outlined how too often service involvement methods may inadvertently under-represent this diversity and present a more homogenised profile and set of views of a particular group. As this quote from a Roma participant describes, whether this limitation reflected a lack of resources, or a lack of understanding of diversity within and across groups, its impact can be a dilution of difference:

> *I think (a lack of representative consultation with Roma would be a problem) because of the transitions (traditions) and the cultures. Because literally every Roma from different communities have different cultures, different transitions (traditions), and that would be a very big problem.* (FG.PWLE.MM.RO)

BOX 6.1: The Covid-19 Pandemic & Service Involvement

The Covid-19 pandemic exposed and exacerbated inequalities for many of the groups in this study, spurring on calls for service involvement to help address these inequalities:

> *...we recognise particularly in the context of COVID those with the most, you know, the worst health outcomes suffer disproportionately and in many cases unnecessarily. So I think you know for the HSE to be seen as actually spearheading this [service involvement]… would be seen as ground-breaking...* (IN.SH.08)

The Covid-19 pandemic catalysed some positive change in services, but impacts were more - negative with greater pressure on services, deficiencies in care and service access and damage done to relationships and trust.

> *I have experience with…someone from my family: he need to make operation and he was not allowed nobody to go with them. Because he was in hospital with this kind of COVID, it was very, very strict you…they don't have translator, how I can explain our issue, what's happening after operation, to explain to give us some update you know. (FG.PWLE.MM.RO)*

The impact of the Covid-19 pandemic on service involvement has inspired some positive innovations and developments. This included new more effective systems being put in place for feedback, and greater use of virtual tools. The service provider survey found that 20 per cent of service providers in part, or mostly, redeveloped their service involvement activities to online engagements. Nonetheless, there are of course challenges in this regard because of varying levels of digital accessibility and literacy amongst population groups.

> *Even when they were doing research online or they're doing questionnaires online…during the pandemic…with the Traveller community…you'll not get the same level [of engagement]. If that form was sent out to my mother-in-law or any members of the family that couldn't read and write and they're not really understanding what it is, they wouldn't do it. That's just reality.* (FG.PWLE.TR.DO)

But impacts on service involvement were mostly negative with 78 per cent of service providers saying their activities had been impacted: 19 per cent reported how activities were delayed, whereas 14 per cent said they were cancelled. This means that a lot of momentum which had just begun in recent years has been lost. The pandemic also exposed a lot of learning regarding weaknesses in approaches to service involvement. In some cases, involvement activities were not viewed as core to services' work and deprioritised. In other cases, previously inflexible approaches highlighted the need for more person-centredness in designing engagements.

> *… I just think of the areas that we did have a lot of learning… at the outset of Covid…it was incredible, there was a time when a lot of obstacles were moved, you know out of the way. So sometimes referral processes can be complicated, maybe accessing drug treatment, or… drug substitution therapies, or whatever, and there was just a huge amount of flexibility, you know was kind of available from all systems, from all sides of health and social care at that stage. And I just think some of those learnings need to be maintained in this, because again sometimes you can… the procedure takes precedence over people – you can lose people – and we really learnt there was kind of a willingness*

to start looking at the solution rather than always getting stuck in the process. (FG.SP.HO)

For others, such under-representation was thought to reflect a more long-standing and pointed neglect of the voices of particular groups. This can lead to a strong sense of exclusion from decisions, discussion, and, as this female lived experience interviewee describes in the context of her experiences of having used club drugs, exclusion from important supports:

> *…they told me at the [named residential treatment centre] that they'd never had, I was the first person whose drugs of choice were amphetamines… The system doesn't recognise it, and it still doesn't…It took a lot of work on my behalf, but I didn't have any like keyworker or counsellor or anything like that. I just did it myself like… trying to get me into a treatment centre. Trying to, you know, source the detox, blah, blah, blah. So 14 months later, [named service provider] rang me and he said, 'I'm just ringing to let you know, that we can't provide the service that you need'. I said, 'Do you know what, I really didn't expect anything less from you'.* (IN.PWLE.DA.01)

A third and final challenge around representation, related to the recognition of individual identities and experiences within groups. For several individuals this meant being viewed as individual people rather than being viewed through the lens of labels arising from their ethnic or migration status, or their experiences. It also meant not overlooking the intersectionality (and thus complexity) of their experiences and needs. These points are illustrated by a person who had experienced mental health challenges and drug and alcohol use, and who felt that services had stripped his personhood and failed to recognise his sense of personal identity:

> *[Services should be]… helping a person achieve their goals instead of, you know, having the services saying, you know, just take your benefits, stay at home, don't achieve, you know? You get the feeling just because, you know, I've a diagnosis of schizophrenia, hearing voices we'll call it, I get the feeling [that service providers think] 'you're not like one of us', you know? 'Don't try and achieve, you know? It's sort of... 'Just be happy', you know… So, it's them limiting beliefs [that are problematic].* (FG.PWLE.DA.RE)

Stakeholder interviewees and service-provider focus group participants noted that having broader representation forces consideration of a wider range of perspectives. For those who had experiences of where this sort of representation was incorporated into service involvement, explicit benefits were described. As this national stakeholder describes, these benefits can include an understanding of the nuanced religious and cultural differences within groups:

> *And we also had a lady who was a refugee originally...She was with us for two and a half years and she was marvellous because what she did, which was brilliant, she brought anything new, anything we were doing on our committee on the patient council, she would [bring] back to get their views, which was brilliant. So, she kept us very grounded on 'Does everybody understand it?', 'What about different religions?', 'What about different traditions?' and everything else. So, yeah, it was really, really interesting. And actually, it was more representative than say we would have had in the past. So, it was good.* (IN.SH.03)

The importance of representation was noted by some lived experience participants from all five population groups in the study. Some of these participants also explained that there can be an important role for an individual or a small number of individuals to systematically gather the views of a wider set of population groups and convey these views back to the services. One lived experience focus group participant thought this sort of approach would be effective for communicating the views of their peers:

> *'... well I think before anyone would want to approach that [form of group-based service involvement], you'd want to get together a large number of people, clients in service, together, to give them ideas, and write down everything, okay? And then come equipped with what…they represent, and maybe have two or three people doing this.'* (FG.PWLE.MH.SE)

6.5.2 Stigma

To some degree, participants in all five populations spoke about the prevalence of stigma and stigmatising processes. This stigma could arise from negative associations, beliefs and stereotyping that are linked to their circumstances, status or prescribed group identities. It was these experiences that some people carried into involvement activities. Ethnic based stereotyping appeared to be most prominent for members of the Traveller and Roma communities, with these groups discussing resultant marginalisation in many areas of life. However, other forms of stigmatisation – for example prejudice, ignorance, rejection, labelling and perceived loss of status – were an issue for those who use drug and alcohol services, those experiencing homelessness, migrant individuals and those who use mental health services. Most lived experience participants described experiencing stigma in general life contexts, whether in consumer, education, work or social situations. This is illustrated by the following quote from a migrant interviewee who regularly experienced prejudiced attitudes in her work life when her professional views were not valued in the same ways as those of her Irish colleagues:

> *I (am) tired to being judged by people….all the time…it's still now. I'm still facing judgement when I'm doing something good but people doesn't like it because it's come from me, it's not come from someone that they prefer. Even though, in my job place, where I'm working…the same conversation, if I pass it to my colleagues, like I say, it's an Irish person and then that will go from that person, it's going to be heard.* (IN.PWLE.MM.03)

However, many lived experience participants had also faced stigma in a health or social care setting. People talked about: being spoken down to; service providers treating them as being lesser or other; negative beliefs about their culture or community. One male interviewee who was experiencing homelessness described how a stigmatised attitude about his drug use history resulted in poor treatment for a painful illness:

> *I got shingles one time living up in the park, I didn't sleep for five nights. Took three seizures on Grafton Street. It comes up on that screen – heroin addict, methadone addict. 'Ex' doesn't matter…they say, 'Is there any pain anywhere else?' I go, 'I'm in awful pain here', and they turn around and go, 'Ah yeah'… they're thinking you're looking for fuckin' opiates*. (IN.PWLE.HO.05)

While some service-provider focus group participants from the drug and alcohol and homeless discussions noted that they and their colleagues did not stigmatise those who use their services, they acknowledged that this may not be the wider experience of those in care:

> *…I also think when it comes to stigma or marginalisation, we can sometimes get a bit*

> *of a skewed insight when we're in the homeless services, because we tend to assume that everyone understands that people aren't to blame for their own position, you know that poverty isn't their fault. So we can get a kind of a rose-tinted lens of people's attitude towards homelessness…*(FG.SP.HO)

It was also evident that the normative nature of some stigmatised attitudes can be internalised by different members of the populations. Participants and service providers described how such self-stigmatisation can lead to negative outcomes such as societal self-exclusion or delayed and disrupted care. For some participants this was described as having manifested as a reluctance to seek support or accept a diagnosis and/or a course of treatment. This participant talks about how his own stigmatised views of (his own) mental illness meant he resisted treatment:

> *I gradually stopped…[taking my medication]… I started skipping days …but I got really bad then and…I did realise that it was completely the wrong thing to do and I had a whole – my attitude towards anti-depressants was an unhealthy one and [my psychiatrist] was saying to me, 'If you had a heart condition…you'd be on medication and you'd take that medication without question. If you had a respiratory disease, you'd be taking medication, an inhaler or medication…'* (IN.PWLE.MH.04)

6.5.3 Discrimination

Participants in all phases of this research discussed how the five population groups can be treated in a discriminatory way, with a pervasive view that experiences of discrimination can be commonplace. Almost all groups were considered to have encountered discrimination in general society, and within the health and social care sector. At a societal level, lived experience participants discussed unfair treatment based on issues such as intellectual disability or neurodivergence (participants who used mental health services, and homeless services), or due to drug use. Within services, unfair treatment could be evident in a lack of access to care services and supports (for example due to migration status), a poor level of services (for example poor quality accommodation or food because of homeless or drug use status), or differential access to financial services (for example mortgage products for migrant individuals). The following quote illustrates one participant's view that the food she was served in one homeless service was of extremely poor quality and a health hazard due to a negative and prejudicial view of people with a history of drug use:

> *[The food was] very, very poor and that's in [temporary accommodation service]. That's a place that should be… really needs to be looked into, very properly. I got food poisoning six times out of that food. I ended up in hospital six times…No, what they do, instead of putting the fresh dinners out, they're putting the old dinners to the front and the fresh dinners to the back…because you know why, because they way they look at it is you're an ex-addict or your this or you're that.* (IN.PWLE.HO.04)

For those with intersecting experiences, or statuses, for example people in homelessness with a history of addiction, discrimination could be intensified and more keenly felt.

For those of different races or ethnicities – individuals from Traveller, migrant, minority ethnic, and Roma communities – the discrimination they faced was most often encountered as racist behaviour and treatment. For Roma individuals, it was felt that service providers could treat them rudely because of their ethnicity and this was particularly the case for those Roma who cannot speak English with a high-level of proficiency. Service provider and lived experience participants argued that special consideration should be given to those for whom English is an alternative language (migrant group) or indeed to those with literacy issues. A lived experience participant from a migrant background explained the importance of providing language supports:

> *'…English is not my mother tongue. For some people doesn't know like a complete survey will be good if someone helped them read it, explain them and do it, if the person say yes, you take it, if it's no, across. At least someone can help them to do the survey, and the survey should not be like on the paper and go to the bin or go to the trash. The survey should be useful really like, you know, not just on paper black and white. Then it's a survey, then it's a really good job but if you just do it, like we'll say we're using paper or then it go to the toilet, you know what it mean. Used paper in the toilet.'* (IN.PWLE.MM.03)

However, it was Travellers and their representatives who were most vocal about what they felt was poor-quality engagement within health and social care due to discrimination, and racism, which varied in form from direct to indirect, and implicit to explicit. Connected to this, it was argued that Travellers are often not heard, and this can be, at least in part, due to poor communication and resultant misunderstandings. This is borne out by the service-provider survey data for the Traveller group which found that 'fear of discrimination' was the primary barrier to service involvement for Travellers (63% agreed 'to a moderate extent' and 37% agreed 'to a large extent' that this was an issue; 'fear of discrimination' was not such a prominent barrier for the four other groups). One stakeholder, with a remit for Traveller services, noted evidence that racist discrimination can be pervasive:

> *… I mean if you look at the All Ireland Traveller Health Study …7 out of 10 said, 'Yes, anti-Traveller racism exists within the services', and Travellers get a lower I suppose or a substandard treatment as a result, so I think like we can't pretend that that doesn't exist, so I think that does need to be named…*(IN.SH.08)

For Traveller individuals who experienced discrimination and stereotyping, the impacts could be substantial. It is in this light, that a number of Traveller participants spoke about how engagement in care services, and in service involvement activities, had to be framed within the multiple disadvantages that discriminatory treatment generated. As this man from the Traveller community describes, the cumulative impact of this discrimination can amount to a social alienation that ripples through daily life, and becomes entrenched within the psyche of individuals and groups.

> *…the discrimination that we face daily, if it's going into a shopping centre, into a restaurant, into a pub. If it's walking past a settled person on the street. If it's somebody driving by in their car and they're throwing us looks through their window and they don't even know us but because we're a Traveller walking down the street, do you know what I mean. You have to stand in a Traveller's shoes. The minute a Traveller opens his eyes in the morning, and takes a foot into the outside world till the last foot he takes at night back inside his own door, he faces discrimination…you're being looked down at. You're being contradicted. You're nearly put as a liar. You're being shamed from the people that you don't want to be shamed of. There's so many consequences that go on and go on and go on that we daily face, and it's a constant daily struggle…* (IN.PWLE.TR.05)

It was apparent that many study informants felt that discriminatory treatment experienced by any of the population groups within the health and social care services would result in negative health and well-being outcomes for those using services. This in turn was thought to lead, again, to less trust in systems, the exacerbation of already poor levels of communication, and less engagement by those with lived experiences in care services and service involvement.

6.6 Key Messages

Leadership and commitment

1. Study informants, especially stakeholders and service providers, felt that there were gaps in strategic direction and prioritisation, which manifest as insufficient policy, strategy, and drive. These in turn impact downstream on involvement implementation.
2. There were concerns about a deficient culture and ethos of involvement in some organisations, where engagement was not consistent, sustained nor sufficiently embedded for these groups, and little or no follow up action was normalised.

Implementation and action

3. Participants felt that service involvement processes were not happening in a satisfactory manner, due to under-resourcing (budgets; staffing; training and participant renumeration), a lack of measurement standards, and a lack of accountability, resulting in insufficient improvements for service delivery.
4. Service providers reported fatigue at a lack of follow through on service involvement outputs, while many lived experience participants felt their views were not valued and that processes were often tokenistic.

Population Capacities

5. All study informant groups (national stakeholders; service providers; lived experience groups) agreed that the capacities of lived experience participants need to be considered in service involvement. Some participants may not be psychologically ready to take part, may not have the confidence or self-esteem to participate, and may not be familiar with the processes of involvement.
6. All study informant groups noted that lived experience participants bring considerable strengths (due to service and life-course experiences) to involvement processes that can be harnessed.

Trust

7. There was good agreement across all study informant groups that trust was a key factor in service involvement with these populations and could be driven by a wider lack of trust in structures and systems, and/or negative experiences of dealing with individuals in services, or service involvement activities.
8. Trust was also influenced by trauma-based fears around certain places, spaces, people and activities, and by perceived and actual threats to privacy and confidentiality and the implications of sharing their honest views.

Representation, Stigma and Discrimination

9. A lack of sufficient representation, stigmatised attitudes and discriminatory treatment are factors which people from all five groups in this study faced to varying degrees, due to their status and experiences. For some, their circumstances can intersect, or can be internalised, thus intensifying exclusionary outcomes.
10. Previous experiences of stigma and discrimination were often present for members of most of the lived experience groups and arose from general interactions within society and from within the health and social care systems. These experiences resulted in distrust and were thought to inhibit effective service involvement.

Peer Research Case Study 5 - The Traveller community and lived experience in Service Involvement

By Michael Mongan and Kieran Mongan

Michael and Kieran, who are both members of the Traveller Community, worked together to detail what they consider necessary for full inclusion in service development and access to services for Travellers. Michael and Kieran highlight three positive outcomes in their community, which arose through service engagement with members of the Traveller community: a weekly football session, a report on mental health among male Travellers, and a sculpture donated to a local fire station.

Inclusion in a healthy way – *Michael and Kieran (with editorial support from ICSG)*

We chose this photo as it best represents the 'Men's Health Initiative' by showing our football pitch. The football came about as a result of having our voices heard on service involvement. A focus group took the time to ask what Traveller men needed, what they wanted to see happen. Donegal Travellers Project runs a weekly football group for men aged between 18-60. We meet every Tuesday to play football, and this helps the men get exercise and a break away for a few hours. This means a lot – it can be a lifeline for those who don't have places to go for a break. This photo of our football pitch recognises the inclusion of Travellers to socialise in a healthy way with others in our community. The photo shows how people can come together through football. Like It's an outlet, for Travellers to make friends and socialise. Like they can't always get served in pubs, so they spend a lot of time at home and they might drink more there, so this is a way of getting them out of the house without drink being involved.

Giving voice – *Michael and Kieran (with editorial support from ICSG)*

This photo highlights a report that researched the mental health of Traveller men in Donegal. The advisory group was made up of Traveller men with experience of working in the

community. Travellers have all reported negative experiences when trying to access any services in Donegal. This research gave them a voice and created recommendations to ask that services be made more inclusive of the Traveller community. We feel that reports like this one on Traveller men’s health point the way to practical things that can benefit Travellers. The report tells how Traveller people need to be considered appropriately when trying to access services.

A sense of belonging – ***Michael and Kieran (with editorial support from ICSG)***

This photo is a sculpture of a fireman’s helmet outside of the fire station in Letterkenny. This sculpture was designed and made by Travellers in Donegal as part of a bigger project. Travellers are often excluded and made feel like they don’t belong. The helmet makes these Travellers feel like they are part of society, no matter what they are told. When you look at a lot of Travellers, I think this gives them something. “Look we made that”. It’s like we belong more because of it. This makes us belong more in the area. Something that was designed and made by Travellers. It could be there 15 or 20 years.

Conclusion – ***Michael and Kieran***

We need consultation with Traveller organisations, and also inter-cultural training. Ireland is very diverse, it should be a standard thing. We have a big Traveller community in Donegal – 400 families, and they’re all different, and some are remote, so we need everyone to be included. We are involved, like we did our own research there, and it showed that we have access to services, but the outcomes are vastly different. We’re not being included in decision making. Like mental health services, the help coming out of it is vastly different. You don’t come out feeling that you’ve been helped. The thing that you went there for – you haven’t got what you wanted.

We need representation to help make decisions. They should link in with Traveller groups when they are making decisions on services. If they are creating services they need to be talking to us. We need to be consulted in advance. They don’t know about our culture, but they make decisions on our behalf. Some things have improved, others have a long way to go.

7. Discussion

The aim of this research study was to investigate service involvement in health and social care services for those who use drugs and alcohol, those who experience homelessness, those who experience mental health challenges, those from migrant, minority ethnic and Roma backgrounds, and members of the Traveller community. With a view to informing the implementation of current and future HSE Public and Patient Engagement programmes for these groups, this work sought to identify the existing levels of engagement in service involvement, the meaning associated with service involvement, and the barriers and enablers related to involving members of these groups in the design and delivery of care services that they receive. The chapter begins with a brief discussion of the study's limitations. The chapter then draws together the overarching findings, discussing their similarities and differences with respect to the international research literature on service involvement. This is followed by an assessment of what separates these groups' situations collectively, what group and sub-group specific circumstances emerged as necessary considerations from the research, and what dimensions of these findings might be unique to the Irish context. The chapter ends with a critical reflection of research and its focus on service involvement.

7.1 Research Limitations

This research has five primary limitations. First, the research is unlikely to reflect the complete range of views related to service involvement for each population group. Although lived experience input was maximised within the agreed scale of the study, and recruitment strategies were designed to optimise representation, the capacity of the research to fully capture the diversity of perspectives through the number of lived experience participants included per population must be noted as a limitation. The research should therefore be considered exploratory in nature, with further work required to expand the consideration of these populations in relation to service involvement. Second, and even with the limitation in scale, it has not been possible to represent the depth and breadth of participants' lived experiences within the confines of this report. This included a full exploration of how life-course factors and intersectional positions and circumstances could inform views and expectations. Third, the low response rates from service providers serving some population groups, and the lack of visibility/control over survey administration, limits the generalisability of survey findings. Although all efforts were made to avoid and limit the impact of these challenges, survey results have to be interpreted in this light. Fourth, and as often with studies of this nature, there is a potential that the views of those members of these populations who were less connected to the health and social care system, or those who were most in 'need' of engagement, were not captured within the study. While again efforts were made to implement recruitment strategies to capture these views and voices, it is important to acknowledge this possible limitation. Fifth, the timing of this study, with respect to occurring in a post-Covid-19 context (amidst issues around staff recruitment and exhaustion) and coinciding with major crises in housing and migration, limited the capacity of some organisations to be involved in the research. This was in terms of organisation's providing their own perspective, and in terms of facilitating the recruitment of lived experience participants. Even for the research team, there was certainly points in the study's implementation where there were questions of whether this topic was sufficiently 'urgent' to distract supporting organisations from these crises and their core activities. A counter argument, of course, may be that this was precisely the time to conduct such research, when relative priorities and gaps in resources come most to light.

7.2 Significant Activity Levels – But Not the Full Picture

The findings of the research suggest that there is, in overall terms, a high-level of service involvement activities happening with the populations. This activity, however, is not always of high quality, varies in absolute terms across the groups, and does not always sufficiently engage members of the groups in daily practice.

While differences in rates of activity across the groups must be interpreted with caution – given the small number of organisational survey respondents for certain populations, or the likely underrepresentation of mental health providers – there is sufficient evidence across the research strands to indicate high levels of engagement. This reflects the efforts that have been made to enhance involvement for many of these populations at a grass-roots level, as well as the higher-level focus on engagement that has been targeted within some population-specific strategies. For some groups, such as migrant, minority ethnic and Roma communities, service involvement is still in its embryonic stages but has grown in significance. For other groups, such as the Traveller community, there are long-standing examples of community-led partnership approaches, such as the Primary Health Care for Travellers Project, that embody the core principles of involvement, but with perhaps fewer examples of engagement within the mainstream care system. In terms of mental health, and as might have been expected, the findings highlighted a more established track record of involvement and a more intensive co-production and peer support focus. Whereas the integration of lived experience perspectives within drugs and alcohol services has increased significantly.

The findings suggest that these trends, however, also mask limitations in existing involvement for these groups. These include: (1) the concentration on less intensive forms of involvement for most groups; (2) a tendency towards more superficial engagements; (3) a lack of coordination; (4) and a lack of harmonised approaches. The latter two points reflect findings from recent research with mental health services within a number of CHOs, which found different levels of experience in engagement activities across CHOs: over 71 per cent report engagement in CHO1, compared to 64 per cent in CHO8, and just 33 per cent in CHO2 (CHO 1, 2023; CHO 8, 2023; CHO 2, 2023). Reflecting the assertion of many study informants, service involvement for the five groups, therefore, remains not as established a practice as it needs to be within the care system. This is in terms of a meaningful depth and a standardised breadth of activity. Despite the significant advances in involvement within mental health services, there was clear frustration that a sufficient step change in the quality of services, and in the value placed on lived experience involvement, has not occurred. These findings mirror international patterns documented for similar populations in other country contexts (Williams et al., 2020; Richards and Snowcroft, 2020; Andrews and Heerde, 2021).

Service involvement for the groups also appear to exist in an information asymmetric environment, where awareness of such activities amongst the populations was often narrow. While this was more of an issue for some (those in homelessness; migrant, minority ethnic and Roma communities) more than others (drugs and alcohol; mental health) a lack of awareness was evident to some degree for all populations – patterns, again, found within the international literature (Chauhan et al., 2021a). Across the 136 lived experience study participants, there was only limited evidence of direct involvement. Of course, and as with the wider population, individuals may have participated in engagement activities without fully comprehending, or more problematically not being fully informed of their purpose. That said, it would be prudent to assume that a significant deficit remains with respect to direct experiences of involvement amongst these populations. This is particularly in relation to engagement beyond individual care planning, at the organisational level and especially at the broader practice and policy levels. Previous research has highlighted that initiatives in this space have been slow to trickle-down to these and similar populations and when they do, they are largely concentrated within individual care scenarios (Condon et al., 2019; Horsell, 2022). Others have gone further, noting that these groups remain in an engagement operational vacuum, where implementation of service involvement exists at a distance from these groups (Mulvale et al., 2019). What is clear is that without real change – in the form of conscious action to address these deficiencies –service involvement will not be established as a daily meaningful practice, nor a strategic tool, for the five populations.

7.3 Consensus on Meaning, Goals and Room for Improvement

The broad consensus on the meaning and goals of service involvement testify to how the informants in this research, at national, organisational, and individual levels, saw value in involvement, and its potential to affect positive change. Although articulated in different ways, there was consistency in the view that involvement should: improve evidence-informed health services; should target a greater centralisation of those who use services in decisions; and, ultimately, should target better well-being outcomes. Therefore, service involvement should lead directly to action and impact. Within these wider ambitions, it is notable that there were differences with respect to the goals that were emphasised by different sets of informants.

For national stakeholders, particularly those with policy/practice coordination remits, there was generally more of a focus on involvement supporting long-standing policy agendas related to health and social care, where transformational change is slow to emerge (Suter et al., 2017). There was thus recognition of how involvement may potentially function as a strategic tool for translating high-level objectives into on-the-ground improvements in areas such as person-centred care reform, transparency in services, and Public Sector Duty with respect to rights. This is likely to reflect both the sticking points within the current health and social care policy landscape (Burke et al., 2021), and the wider discourse concerning the role of engagement in European and international policy spheres (Andreassen, 2018).

Amongst service providers, and particularly as elaborated within the focus group discussions, there was an interest in the transformational role involvement can play in culture change within the care system. This was primarily evident in descriptions of the imbalance of power within service exchanges. Providers highlighted involvement as a possible means to enable an equitable redistribution of power towards those who use services. The emphasis that providers placed on empowerment was very much in a similar vein, asserting that greater voice had to be given to these populations. While there was not a substantial difference across providers in this respect, those working in mental health services were more likely to highlight this role given the documented influence of a traditional medical model in discounting the views of people with mental health challenges (Damsgaard and Angel, 2021). More generally, the emphasis on power and empowerment is likely to reflect providers' experiences of the potential for system-based marginalisation of not just these groups but of the very care services they use. This has also been noted within previous research (Campos-Matos et al., 2019; Staniforth and Such, 2019).

For those with lived experience, the need for being heard and for empowerment was linked to a desire to counter not being included and valued in the past. Given the weight of this experience, it was not surprising that participants recognised the value of service involvement, despite their lack of awareness of formal involvement practices. It was also not surprising that it was this aspect of service involvement that was most referenced by those whose agency could be assumed to be diminished in some form, such as those who use drugs and alcohol and, again, those living with mental health challenges (Gordon et al., 2021, Phillips and Kuyini, 2018). The focus on other goals is likely to be similarly grounded in their social positioning as members of these groups. In the case of capturing a diversity of perspectives, it was clear that members of some groups felt that their specific needs were overlooked through a more homogenised, stigmatised and discriminatory view of their broader population. This, for example, was the case for participants who had experience of drugs and alcohol – particularly those who were members of specific drug culture communities (club-based drug use or chemsex) – and for those who were from migrant backgrounds – particularly members of the Roma community. In the case of understanding life-course circumstances as documented in international research (Abraczinskas et al., 2021), many participants felt that the level of accumulated disadvantage that they experienced and how it impacts their health was neither fully comprehended nor truly believed.

It is clear that there is a collective desire for service involvement that is not just involvement, for involvement's sake. Taken together, the research findings signal a call for a form of involvement that drives change – certainly in terms of individual level outcomes but also in terms of the inclusiveness of the health and social care system, and the position of the five groups in relation to that system. Follow-through and action must be key features of engagement processes. National stakeholders, service providers and people with lived experience were able to highlight service involvement initiatives that had generated meaningful impacts. In the case of stakeholders, this was at the level of national programmes that adopted general principles of engagement, such as the National Patient Forum. People with lived experience noted services or peer-groups that marked a significant improvement in the quality of their services, and the degree to which they felt listened to. These examples represented genuine turning points in people's lives and how they were empowered to engage in their health and social care. However, by and large, these examples were often timebound, in their early stages, or limited local grass-roots initiatives led by just one or two individuals. Others, even longer-running examples, were subject to conditional funding renewals that impeded their embeddedness and hampered their development. It is for these reasons that discussion of the goals of involvement was often in aspirational terms. It is also for these reasons that while there may be individual activities for these groups that are of a high standard, they operate within a landscape that is characterised by activities of varied quality that may often lack coordination, strategic direction and a capacity for sustained action and change.

7.4 Significant Challenges to Overcome and Harness

The challenges presented in this report represent factors that shape the wider service involvement environment. These challenges are in line with those previously found to influence the efficacy and sustainability of involvement strategies for groups susceptible to unequal service access, and prolonged social exclusion. This is both with respect to international jurisdictions, and the Irish context (Gathen et al., 2022; HSE Social Inclusion, 2023). Consequently, and with reference to those challenges identified by the research literature in section 4.2.7, the factors can similarly be categorised as health and life-course considerations (Andrews and Heerde, 2021), communication, esteem and engagement issues (Beresford, 2020), organisational and service factors (Larsen et al., 2022), and systemic deficiencies (Madden et al., 2020).

While the first two challenges (leadership and commitment; implementation) by and large speak to system and organisational factors, it was not just national stakeholders and providers who highlighted their significance. People with lived experience described how these factors influenced the degree to which they were centralised within the services they received.

In terms of leadership and commitment, previous research has shown that service involvement will be ineffective in driving sector-wide service quality when it operates in isolation, without strategic direction or a multi-level structure that prioritises, governs, and regulates activities (Palumbo and Manesh, 2021). Where the culture and processes of a system, or an organisation within that system, fails to embrace involvement, then the development of a genuine ethos of engagement is unlikely to evolve or to persist beyond time-bound projects. Irish research has recently found that just under half of respondents in surveys of Irish mental health service providers either did not want to or were not sure if they wanted to get involved in patient engagement (CHO 1, 2023; CHO 2, 2023). As previous international research has also found (Moore and Zeeman, 2023), there was some evidence in this study to suggest that service involvement can be beset by a reluctance to break from a profession-led and/or clinical hierarchical governance model. Although primarily spoken about as arising in the past, stakeholders, providers and people with lived experience did note the reluctance of individuals in some professions to accept lived experience perspectives and peer roles within decision making structures – with, in some cases, both clinical and managerial professions resistant to reforming hierarchal structures that favored the power of professions. Indicative of the barriers to change addressed within literature on complex health care system reform, this points to the need to consider resistance from communities of practice or from a fear of losing control amongst professional actors (see Baker et al., 2018). Professional resistance also points to how embedding involvement will require harnessing engagement as a relational process that supports open dialogue (Shore and Kupferberg, 2014; Baumann et al., 2022). Without addressing power imbalances, and the impact of service involvement for different actors in the care system, the voices of those who use services may remain a very minor part of practice (Patterson et al., 2010).

With respect to implementation, there is an extensive literature that indicates the interdependency between resourcing, monitoring and evaluation as key success factors in service involvement and the consequences for governance and impact when they are not in place (Burgess and Choudary, 2021). Previous research has shown the limitations in leveraging these resources within, what are in many countries, the marginalised service sub-sectors that cater for excluded populations (Campos-Matos et al, 2019; Staniforth and Such, 2019). As a result, difficulties in embedding a partnership approach to involvement, that avoids a tendency towards tokenism for these groups, have been well-documented (Miler et al., 2020). Also documented is how the challenge or success of implementation in complex health and social care systems is largely determined by the characteristics and particulars of different implementation contexts across levels (Baker et al., 2018; Carlfjord et al., 2010). This means, in the context of the Irish health and social care system, that macro-level organisational and systems environments have to be considered along with Health Regions, and other meso level settings (e.g. hospital groups), as having to enable implementation led and facilitated locally. Work is still required to promote the value of involvement and to embed involvement as a necessary part of effective care routines and practices for these groups.

Challenges related to population capacities, trust, and representation, stigma and discrimination were similarly intertwined in participants' narratives of service involvement. As noted in Chapter 6, the subjective views of the five population groups were heavily contextualised in people's past experiences of using care and support services, and in many cases their general life experiences. It was also something that was recognised and often referenced by national stakeholders and service providers. Like others have shown, the capacities of the populations for service involvement require specific attention (e.g. Flanagan and Hancock, 2010; Van Hout, 2011). While issues regarding a lack of familiarity with engagement activities suggest a tangible deficit that can be addressed through training

(O’Donnell et al., 2016), factors related to personal psychological readiness and a sense of self-esteem can represent more profound barriers to the development of individual and group capacities for service involvement (Goodhew et al., 2018; Almeida et al., 2020).

Concerns about trust were pervasive in the accounts of those with lived experience, and stakeholders and providers alike, with trust issues being one of the more prominent barriers identified within previous research on engagement with these groups (Wenaas et al., 2021b). Trust is also noted as a central component in the ‘Better Together’ Roadmap (HSE, 2022). Challenges to trust were pervasive (discussed by all but one of the fifteen lived experience focus groups, and by two-thirds of the lived experience interviewees) and were found to foster a culture of distrust and disrespect within the health and social care system. Findings pointed to failures within individual relationships and the presence of more systemic structural barriers. Both factors contributed to a perception amongst many lived experience participants that they were neither valued as users of services, nor that their views would be acted upon. It was also apparent that a culture of distrust was likely to reinforce personal doubts about psychological readiness and self-confidence for engaging in service involvement.

For many lived experience participants in this research, the lack of representation, the stigmatised associations, and the discriminatory actions that they encountered were the principal drivers of distrust and disrespect. They were also the factors that directly undermined an individual’s capacity for involvement, contributing traumas and anxieties that detracted from a sense of wellbeing and efficacy. When these experiences were concentrated within or reproduced by engagement activities – such as within problematic individual care planning, tokenistic consultations, or degrading engagement exchanges – service involvement emerged as another mechanism that could strip power and chip-away at perceptions of self or group worth. As documented previously (Williams et al., 2016; Palumbo and Manesh, 2021), derogatory treatment based on social identities characterised some of the service interactions for some people – whether in terms of service use, or involvement.

7.5 Population and Irish Specific Considerations

As described in the previous sections, the patterns and themes presented in this report are supported by existing evidence, helping to validate the study’s findings. There are though three further dimensions that should be considered in relation to engagement for these populations and the Irish context.

7.5.1 Lived experience populations, exclusion and service involvement

What separates the circumstances of the five groups in terms of service involvement, as populations who have a greater susceptibility to health inequality and social exclusion? Within the general literature, similar trends and challenges have been documented for mainstream populations. Although research evidence pertaining to Ireland is more limited, it is likely that such patterns also reflect the circumstances in Ireland for engagement and the general population. Looking across the findings there are, however, several interrelated factors that distinguish the circumstances of the five groups with respect to engagement activities.

First, the challenges that are identified are likely to be more acute for the five groups and are more likely to impede involvement to a greater extent than for the general population. This relates to: the historic deficit in opportunities for engagement for these communities; the lack of recognition of group diversity; and the associations of reduced agency. It also relates to how, as indicated in section 7.2 service involvement developments may be a little slower to filter down to such groups. Mirroring general issues regarding access to high quality person-centred services, these populations were less likely to have wide-spread access to tailored, and well-resourced service involvement activities. This is notwithstanding the efforts that are evident on-the-ground, or that service areas like mental health may actually be more advanced in engagement programme development than many general divisions within the care system.

Second, the circumstances and experiences of these five groups can introduce additional barriers to involvement. Themes related to psychological readiness and confidence, trust, and representation, stigma and discrimination simply do not feature to the same degree for mainstream groups (Patterson et al., 2010; De Freitas et al., 2020). The lives people have lived, the precarity and risk that people have had to negotiate, and the accumulation of societal exclusions are all factors that demand additional consideration in determining how these groups should be engaged and supported. The need for involvement activities to be effective takes on additional significance given their potential to help circumvent these challenges, or in some cases, if not sufficiently inclusive, to leave some of these groups further behind.

Finally, there was a strong concern amongst many of the study informants that health and social care delivery for the five populations is not always adequately resourced. For those with lived experience, this was a recurrent theme that was situated within their daily lives. Many providers, and national stakeholders, asserted that care for the five populations was: not always prioritised sufficiently; often underfunded in terms of targeted programme budgets; and frequently under supported with respect to workforce training and development. As a result, health and social care for the groups was considered to be, in itself, subject to a form of sector marginalisation. Although some study informants noted the meaningful advances that had been made for these groups, this concern was common across all populations. Many of the characteristics of the current service involvement environment can be understood to be rooted within this wider context. It therefore must be considered how such a context exacerbates challenges in the development of service involvement agendas.

7.5.2 Population specific considerations and differences

How does service involvement in this study differ across each of the five population groups? As outlined in Chapters 4, 5 and 6, the findings presented in this report are robust across the groups. However, as also noted in these chapters, there were some specific group differences in how these findings were constituted.

For those who use drugs and alcohol, the research findings overall indicated that there appears to have been a good growth in service involvement. Local drug and alcohol taskforces were cited as an on-the-ground example of where the integration of lived-experience and peer worker perspectives can be prevalent. The findings also indicate, however, how involvement is sometimes challenged by problematic and heavily stigmatised associations – such as those related to addiction, cognitive competence, and criminality – that undermine connections to health and social care services and that erode individual identity. Furthermore, the drug and alcohol population is a broad grouping that incorporates diverse sub-sections and cohorts, who have very different patterns of drug and alcohol use. The physical and cognitive impact of particular drugs, differences in and location of treatment (residential versus community), and distinct cultures of drug use are all factors that need to be considered in representing this group (O'Donnell et al., 2016; Wenaas et al., 2021b). These factors are likely to determine what supports may be required and how involvement should be designed to capture the full diversity of perspectives within the population.

For those experiencing homelessness, again growth in service involvement activities was highlighted within the various research strands. The disconnection of some individuals from the health and social care system, and society in general, and the transience of some sections of this population can create practical issues for engagement and capacity building. This can crosscut many challenges discussed in this report and has been well-documented within the international research literature (Eriksson, 2023; Meyler, 2021). Moreover, participants in this research emphasised a particular vulnerability surrounding homelessness. Multimorbidity, complex and dual diagnoses, environmental insecurity, uncertainty, and issues regarding social stigma means that service involvement has to be more flexible, more sensitive, and more varied in form. The potential for mismanaged engagement to enhance distrust and exacerbate anxieties regarding care services was all too clear, and evident within the accounts of service providers and those with lived experience alike.

With respect to those who use mental health services, undoubtedly, there were benefits from a longer track record in service involvement. Reflecting some of the patterns internationally (Omeni et al., 2014), it was evident in overall terms that there was simply more involvement activity, more intensive forms of engagement, and more awareness of lived experience perspectives within service design and delivery. For lived experience participants, the longer track-record appeared for some to contribute to: a stronger view of what involvement should entail; a greater understanding of entitlements; and higher expectations regarding the integration of live experience in services. Juxtaposed to this, it was also apparent that there was a damaging legacy from a neglect of voice, and an absence of person-centred approaches, within the care that some participants received during their lives.

For migrant, minority ethnic and Roma communities, service involvement is relatively early in its development. It was evident that the implementation of engagement activities can again be complicated by the diversity of sub-groups within this broad population. While there were signs of efforts to advance involvement activities, the range of service needs, of personal resources, and of migration and settlement experiences within this population meant barriers were encountered in slightly different ways, and at different levels of intensity. As others have noted (e.g. Marjadi et al., 2023), the findings highlighted that there remains a tendency to homogenise the voices and needs of these diverse groups, and to overlook the significance of different ethnicities, different migration channels and different degrees of displacement and discrimination. This is evidenced by deficiencies in collecting information on ethnic or cultural background in Ireland in health and social care research (in a recent study, this was found to happen in just 14 per cent of cases: Hannigan et al., 2020). This is not to mention the ways in which these differences were further patterned by age, gender and health status. As a result, there is a danger that service involvement might evolve as a fragmented disconnected set of activities, and/or fails to sufficiently respond, to the circumstances and lived experience of these groups in a culturally sensitive manner (Kamal et al., 2021; Keane et al., 2022).

Finally, in terms of the Traveller community, awareness of long-standing structural discrimination influenced people’s views regarding service involvement – as did particular issues regarding a lack of change despite extensive past consultations. The partnership approach that has been established by some of the main Traveller organisations, and that has been embedded within key health and social care projects, has also helped to advance understandings of meaningful and peer-led engagements. Nevertheless, and similarly noted in previous studies (Condon et al., 2019; Walsh et al., 2022), there are substantial challenges to building sufficient capacity for involvement across the Traveller community. This includes the small size of the population, the impact of discrimination on trust, the continued low-level of representation in decision-making and, again, the clear fatigue from consultation and research processes that have not produced the desired change. Anecdotally, there is also concern that service involvement and other consultation/research activities, even on an individual basis, can require significant support from under-resourced representative organisations.

Drawing out population specific considerations in this way, while necessary, does run the risk of overlooking the substantial overlap in group membership across these populations. The intersectionality of experiences across mental health, homelessness, drug and alcohol use was extensive, with each also being dominant within the accounts of some Traveller participants and participants from migrant, minority ethnic and Roma communities. For some individuals, who described how they were connected to a set of services that were facilitated through a single organisation or point of contact (such as multifaceted migrant support organisations, or multi-service homelessness charities), this intersectionality appeared to be accounted for by an integrated approach, that built upon their views and preferences. Others clearly felt that the full nature of their needs arising from these intersectional experiences were less recognised and less catered for, with their views and preferences lost in a fragmented system. Just as it is sometimes argued for the intersecting nature of systems of inequalities linked to core status variables and social identities (see Crenshaw, 1989), it seemed that the experiences of some in this research were characterised by an interlocking set of service access and engagement deficits – combining for instance from across mental health, homelessness and drugs and alcohol services. In addition to this, and at a very general level, where these individuals and groups required more specialist consideration due to disability, age, gender, or cultural and racial sensitivities, the levels of meaningful engagement appeared to be lower, and challenges appeared to be more entrenched and complex.

7.5.3 The Irish context and service involvement

What might set the Irish context apart from other jurisdictions with respect to service involvement for the five population groups? As outlined earlier, there are strong similarities with respect to the involvement levels, goals and challenges documented for other contexts, even countries with a longer track-record of engagement with groups that encounter exclusion. There are though four elements that although may not be unique to Ireland, help characterise the specific service involvement environment for the five groups.

As noted by participants throughout the research, there appears to be a deficit in implementation within Ireland’s political culture (also see Connolly, 2023), with ensuing challenges for governance and regulation. While many participants in this study pointed to valuable policies and strategies – setting aside the strategic gaps that remained – they cited a lack of implementation (across the different levels of the health and social care system) as the major barrier in advancing service involvement. Informants spoke about the damaging effects of having little or no resourcing to accompany large-scale agendas in such a complex system, and local initiatives with little capacity to generate action and ‘follow-through’. Some implementation concerns focused specifically on engagement programmes and policies. Others were directed towards population-specific policies, and broader health and social care reform strategies that called for increased engagement, or that promised additional supports to enhance engagement. However, it was not just the lack of resourcing that was the challenge. In the context of a crowded policy landscape, there was often confusion and uncertainty regarding how strategies were interrelated, and which one should be prioritised. This compounded challenges regarding strategic direction and implementation.

The composition of the network of service delivery organisations impacts the service involvement environment, and its capacity and potential for the five populations. Due to the reliance on community and voluntary organisations to deliver services to these groups (Forde, 2020), there is a dependence on these organisations to also facilitate and lead much of the local implementation of engagement for the populations. These providers typically comprise of smaller organisations, who are in many instances operating under significant funding and staffing constraints and are already under substantial strain (see Power et al., 2021). As a result, there is always likely to be difficulty in building sustainable capacity for service involvement, with little room for expansion and standardisation under the current level of resourcing. Questions arise about the realistic nature of ambitions regarding engagement for these groups, if these organisations are not sufficiently enabled for implementation by macro-level and meso-level institutional settings (Baker et al., 2018). Relatedly, while Ireland's small-scale nature suggests the potential for a more integrative approach to involvement, it has also meant as has been shown in this research that good service involvement often comes down to a small team, or individual actors at a very local level. People with lived experience highlighted the influence of a specific service or a particular health professional that championed their needs. Where these actors moved post or retired, involvement stalled with a loss of positive impact, and little in the way of top-down enablement to nurture new implementation and innovation.

Addressing aspects of diversity remains a challenge within the Irish health and social care system, impeding the development of service involvement. A system that supports diversity in service delivery, monitoring and evaluation is fundamental to the representation of the range of lived experiences of the five populations. Across the three sets of informants in this research, participants highlighted the potential for the health and social care system to sometimes homogenise and overlook the perspectives and needs of distinct groups. It was evident that there were symbolic absences where representation of these groups was often missing from sector-wide policies and practices. It was also evident that there were more tangible absences regarding the under-development of inter-cultural competency training, or the failure to introduce ethnic and other identifiers that help track service utilisation, and health outcomes for different population sub-groups. These absences will lower the capacity of service involvement activities to identify, target and engage many of the populations in this study, and their ability to track impact and positive change because of engagement.

The fortunes of service involvement cannot be separated from the tumultuous public health and social circumstances of the previous three years. The combined effects and legacy of the COVID-19 pandemic, the Irish housing crisis, the Ukrainian conflict and migration crisis, and rising cost of living has simultaneously illustrated the need for service involvement, and provided very real challenges to its implementation in Ireland. As presented in Box 6.1, although Covid-19 gave rise to new innovations in engagement activities, the pandemic created practical impediments and delayed the development of service involvement. The legacy of these impacts has drifted into and has been exacerbated by other crises leading to a substantial increase in the demand for certain care services. This has placed significant additional strain on many of the front-line organisations tasked with leading service involvement activities. Naturally, and as has been observed elsewhere (Richards and Snowcroft, 2020), such circumstances have refocused efforts on core service delivery and de-prioritised other activities deemed less essential. Without a change in the priorities that drive strategic and resource decisions, it is difficult to see how involvement can be prioritised within this wider context of provision for these groups.

7.6 Critical Reflection

Looking across the research limitations presented in 7.1, it is fair to say that this research study was beset by some of the same kinds of challenges that can impact involvement activities with the five groups. At various points during this study it was apparent that there was a palpable fatigue regarding any form of consultation and information gathering – particularly when these activities, whether engagement or research related, do not produce observable or meaningful action, and change or do so with sufficient urgency. It was clear that some lived experience participants and representatives of service provider organisations were both frustrated and angered by the lack of return on their investment of time and energy in these activities. For lived experience participants, it was clear that some individuals felt that the emotional cost of reliving and recounting upsetting times in their lives was too high just so as to contribute to an ineffective process. Typically, this frustration was most apparent during initial conversations around whether someone would participate in or support the research, when perceived boundaries between the service involvement, and the research itself were often blurred. Other researchers have also noted the potential for lived experience perspectives to become commodified and treated as commodities within a 'lived-experience market', which does little to actually address critical issues (Eriksson, 2023).

Frustrations and anger were also directed towards the difficulty in accessing information and the lack of an open communication culture within the health and social care system. Efforts around engagement appeared hypocritical to some because of this absence. It seems imperative that those who have responsibility for engagement are clearly identified and that the outcomes from involvement activities, whether successful or not, are clearly communicated. Even during the process of conducting this study, there were times that the research team struggled to identify relevant materials, relevant offices and those who were generally responsible for engagement related activities within the HSE. The historic links and webpages, the lack of contact details, the legacy documents and even the lack of publication dates on policies all point to the uncoordinated piecemeal nature of this area and creates disorientation when attempting to navigate online sites and resources.

In this study, informants were hugely generous with their time, with some lived experience participants and some provider and representative organisations investing considerably in supporting its various strands. This investment of course places an emphasis on the need to ensure there is value and progress leveraged as a result of this report. It also raises pertinent ethical dilemmas regarding service involvement and whether these activities – even if they are in themselves well designed and executed – can be pursued in good conscience where the potential for change might be limited. At local or individual levels, there may be more control over how results of these processes are harnessed and used. But where this potential is weak, it would seem prudent that development of service involvement should be a reflective critical process that weighs up the likely costs and benefits of engagement for all actors. This is the core challenge for senior leadership within the HSE who are charged with the implementation of public and patient engagement within the health and social care sector. Service involvement for these five population groups must not be involvement for involvement's sake. Service involvement must lead to action. And it must lead to positive change.

8. Conclusions and Recommendations: Operationalising an Inclusive and Effective Strategy for Public and Patient Engagement

This chapter presents the conclusions and recommendations of the research. In doing so the chapter focuses on how an inclusive and effective strategy for public and patient engagement can be more readily enabled for the five population groups: those who use drugs and alcohol; those who experience homelessness; those who experience mental health challenges; those from migrant, minority ethnic and Roma backgrounds; and members of the Traveller community. Based on the insights from this research, and representing the core conclusions of the study, the chapter first identifies seven key development areas for operationalising such a strategy. These areas can also be viewed as a means to elevate public and patient engagement as a mechanism for transformative culture change within the HSE and its Health Regions. The chapter then presents the recommendations for policy and practice that cross-cut these areas. Both the development areas and the recommendations are rooted in the research evidence presented in this report and are based on the outline policy and practice priorities and messages coproduced by the Consultative Forums. The chapter ends with concluding remarks.

8.1 Development Areas

8.1.1 Balancing top-down drive and bottom-up direction

A balanced coordinated development of service involvement is required to embed public and patient engagement for the five groups within the health and social care system. This coordinated development must be driven at the levels of national policy and HSE Health Region implementation but informed by on-the-ground local needs and context. It is important to recognise that progress has been made on both. However, this research suggests that progress is not at a scale to generate transformational change and is disconnected across levels, with little in the way of a cumulative advancement. As has been noted for fostering successful change in complex health and social care systems, macro-level organisational and systems levels must enable local action (Baker et al., 2018; Carlfjord et al., 2010).

Coordinated strategic efforts are needed to address challenges in leadership, governance, prioritisation, and implementation for the engagement of the five groups. This should be evident in a clear commitment amongst national HSE and Department of Health leadership, Health Region management teams and professional groups, which recognises the value of involvement, and prioritises, governs and leads its development. In this regard, the HSE Better Together Roadmap may be a useful practice resource. However, there remains a deficit in overall strategy regarding the development of engagement and its long-term direction for these groups. Coordinated efforts must also be evident in terms of an adequately resourced long-term national development programme for the five groups. Put simply, more money, more staff training, more capacity building, more regulation and more performance measurement are needed. Without these coordinated investments, public and patient engagement will be another additional demand that is unsupported and unreasonable given constraints under which services are currently being delivered.

Nevertheless, strategic, and Health Region level drive must reflect the learning that already sits at the level of local organisations and individuals. The establishment of any national development programme should integrate on-the ground knowledge, and lived experience perspectives, within its formulation process. This integration is critical for practical reasons to enhance effectiveness, and for symbolic reasons to assert inclusive ambitions, and needs to move beyond consultation to engagement and co-production. But regardless of national efforts, there remains significant agency amongst Health Regions and provider organisations to prioritise good quality engagement for the groups. Ensuring that organisational decisions regarding appropriate staffing, adequate time and commensurate prioritisation are taken will help move the emphasis from core service delivery to the development of a wider culture of engagement. A part of this culture is to recognise and promote local innovations that are developed in collaboration with or led by those with lived experience.

8.1.2 Connecting the strategic, policy landscape

The range of different strategies and polices that are linked to service involvement is creating confusion around public and patient engagement for the five populations. These circumstances compound the absence of a clear strategic direction for engagement for these groups, and stem from a lack of coherence across the wider policy environment. As detailed in section 1.6, strategies, plans and guides relevant to service involvement can draw in policy and practice domains linked to engagement itself, the five population groups, patient safety, healthcare communication and values, and all-system approaches and frameworks. Just as those with lived experience spoke about difficulties in navigating the health and social care system, service providers and national stakeholders were perplexed at the myriad of strategies and documents that must be adhered to and navigated. Any new policies need to be cognisant of this wider landscape. Through a clearly identified strategic direction, they must also work to consolidate and simplify the objectives and guidance for enhancing public and patient engagement for the five groups. Without regard to this context, it is likely that public and patient engagement activities will become further fragmented, demotivating collective action and local innovations.

8.1.3 Establishing sustained multi-level, multi-form implementation

In addition to a coordinated strategic development approach, there must be an expansion of public and patient engagement for the five populations, encompassing different system levels and different kinds of engagement activity. Notwithstanding some important developments for the general population (e.g. National Patient Forum), involvement activities are currently more likely to be organised in support of individual-level service delivery. A greater embedding of public and patient engagement within organisations is needed, both in terms of informing the design of service programmes and the overall development of organisations. A greater investment in strategic-level decision-making and engagement structures for these groups is also needed, which can impact policy, practice and resourcing decisions. This is within the HSE, its Health Region and, where appropriate, the Department of Health. The research findings also indicate the need for multiple forms of engagement across these levels. Different engagement techniques are required for different sections of these populations and for different engagement purposes. A shift from the dominance of methods that are less involved (e.g. short surveys) to co-production and other co-form and partnership approaches is required – particularly for those groups who have experienced homelessness or those from migrant and minority ethnic backgrounds. Nevertheless, under the inevitable constraints of budgets and time, all methods are likely to serve a purpose depending on the circumstances and the preferences of individuals regarding the means of engagement. A pre-engagement consultation with a diverse sample of the targeted population is likely to be beneficial in informing initial choices. An assessment of how these methods operate over time, or in tandem with each other as a part of a larger engagement agenda, will also be critical to maintain a consistently effective engagement approach.

8.1.4 Measuring effectiveness and action

A key success factor underpinning effective public and patient engagement for the five groups, is the degree to which any information, feedback, or contributions from people with lived experience are harnessed, actioned and measured. The need for action was asserted by all participants within this research and included: calls for implementable tasks and measurable impact; the desire to see real change at a service or system level; or in the case of individuals and groups, just simply the feeling of 'being listened to'. Although resourcing and budgets are instrumental at a broader systems level to support actions, there was a clear sense amongst people with lived experience that it was the commitment to 'follow-through', to do something, that was often key. Measurement, with respect to the introduction of key performance indicators (KPIs), and accountability, in terms of governance and responsibility, must be introduced to drive this follow-through. This must be present at all levels if engagement is to be implementable and sustainable. In addition, there is a case for stronger integration between service involvement stakeholders and structures across all levels, enabling continuity between practices and recommended follow-through activities. As such, actions called for by local engagement practices, should be followed-up on, championed and implemented by higher level engagement structures, and vice versa. Otherwise, engagement as it pertains to the five populations will remain shallow in its embeddedness and narrow in its capacity for change.

8.1.5 Embedding inclusive engagement

The inclusivity of public and patient engagement must be improved to enhance the appeal and effectiveness of involvement for the five populations. In line with 8.1.3 and the need for different forms of engagement, flexible and accessible strategies will improve the fit between approaches and a groups' preferences and life circumstances. As such it is necessary to recognise the distinctions across and within the five population groups. Tailored supports, such as those that account for logistical, financial, and psychosocial restrictions, will address specific needs of groups and the structural barriers that they may face. Inclusive communication, involving a multi-strand multilingual approach using standardised understandable terminology, will help overcome language and literacy issues. Cultural inclusion, in terms of intercultural sensitivity, will help counter discriminatory practices, support recognition of cultural identities and foster an enhanced understanding of a groups' preferences regarding engagement in services. These features reflect those that study participants found helpful to counter the challenges identified in this research. They are also in line with the inclusive engagement models presented in section 3.2.5 (e.g. Hernandez et al., 2010; Snow et al. 2018), and the necessary components identified in the HSE's Better Together Roadmap (HSE, 2023), and by those working with the populations in Ireland (HSE Social Inclusion, 2023).

It is the intersectional positions of people with lived experience that perhaps represents the greatest challenge with respect to developing inclusive engagement. Narrow, prescribed administrative and social identities can restrict our view of these populations to either one-dimensional or single-service user identities. Engagement agendas must be sensitive to these intersections when designing and implementing involvement activities. This is in terms of overlapping population composition, such as the overrepresentation of Travellers requiring mental health services, and of migrant individuals in homelessness

(McKey et al., 2022; O’Brien et al., 2022). This is also in terms of shared experiences regarding aspects like housing, deprivation and recovery pathways through mental health, and drugs and alcohol challenges. It is necessary to foster a full understanding of the intersectional perspectives of these population groups, and the multidimensionality of the challenges that they face. But there is also a need within engagement to reflect the utilisation of multiple and diverse services because of intersectional needs that crosscut the groups. Just as there are active calls for integrated services, there is a need to reach beyond a single service focus by creating greater integration across engagement activities for some individuals and groups.

8.1.6 Building trust as a prerequisite and as an outcome

Public and patient engagement for these five populations is intrinsically linked to trust in structures related to engagement, and the health and social care system, and is fundamental to the other development areas. In this manner, trust serves as a prerequisite for effective public and patient engagement. Issues of distrust reflected not only the weakened ties between these groups and wider society, but also perceived breaches of trust when using or trying to access care services. As others have noted for underserved populations, successful partnerships in the design and reform of services requires an understanding that all actors will interact fairly (Dadwal et al., 2017; Lee et al., 2019). Trust is also critical in recognising, defining and addressing the sort of disparities that are likely to be targeted by engagement activities (Wesson et al., 2019). Building trust must, therefore, be viewed as a core constituent component of the early stages of the engagement process. However, the link between trust and engagement also reflects a mutually reinforcing relationship. Public and patient engagement has in itself a core role in rebuilding trust in the care system for these populations. Reciprocal relationships – founded upon common goals of equitable communities, acceptance of mutual self-interests, and joint gratitude – are critical in trust relations between actors in complex systems (Adam and Donelson, 2022). Longer more sustained engagement, implementation, and action will certainly help establish trusting relationships, as will meaningful opportunities to input views on services. But key to all of these elements is the need for transparency and clear lines of communication. Transparency around the purpose of engagement, transparency around what is involved, transparency around outcomes, and transparency around the constraints that will challenge/impede follow-through actions. Therefore, while desired outcomes may not always be achievable, a genuine honest process certainly can be and must be. This again points to a need for an effective system of accountability and governance. It also points to the need for communication and appropriate regulation that helps engrain a culture of transparency.

8.1.7 Driving an equalising, agency empowering agenda

Public and patient engagement must drive an equalizing approach for the five population groups. This is in terms of health and social care service access, opportunities to express voice, and well-being and inclusion outcomes. Engagement must therefore aim to address both the power imbalances that can develop within a traditional, professionally-driven health and social system, and that can arise from the gaps and deprivations that more directly stem from how such systems view and treat these groups. Whether based on specific grounds within equality legislation, or declarations of rights with respect to health, public and patient engagement must be underpinned by values of equity and fairness. Being engaged in the design and delivery of health and social care services should function to empower the agency of individuals and groups with respect to the quality of services they receive. As a mechanism within a social determinants model of health to affect transformational change, this has been a long-standing call for such populations (Marmot, 2010). Without overstating its impact, an effective service involvement agenda has the potential to engender a greater sense of social integration for these groups, by enhancing a sense of control and efficacy, and by securing the health and inclusion outcomes that informants in this research desired.

In this regard, there is likely to be value in bestowing upon public and patient engagement the ambition to create a clearer path towards full membership of society – embedding a social citizenship (Marshall, 1956), and its elements of civil, political, and social rights, within people's expectations and goals for health and social care. There are many factors that should be considered to enable the empowerment of agency. The identified investments in capacity building, in training and in health literacy across the population would certainly assist. So too would the development of a life-course trauma-informed approach that draws out a more considered understanding of how people's circumstances have evolved over time, the factors that have supported or impeded those circumstances, and the agency that have enabled those within these groups to negotiate these factors. Central to this, however, is a resource allocation model that prioritises these groups' well-being and inclusion outcomes of these groups, and that distributes a larger more appropriate share of resources to public and patient engagement for the five populations.

8.2 Recommendations and their Framing

Fifteen recommendations are presented for advancing inclusive and effective approaches for public and patient engagement for the five populations in Ireland. These recommendations are rooted in the lived experience evidence and the conclusions presented in this report and, critically, are based on the outline policy and practice messages coproduced by the Consultative Forums. The recommendations are therefore driven by the insights and experiences of the participants in this research study pertaining to service involvement.

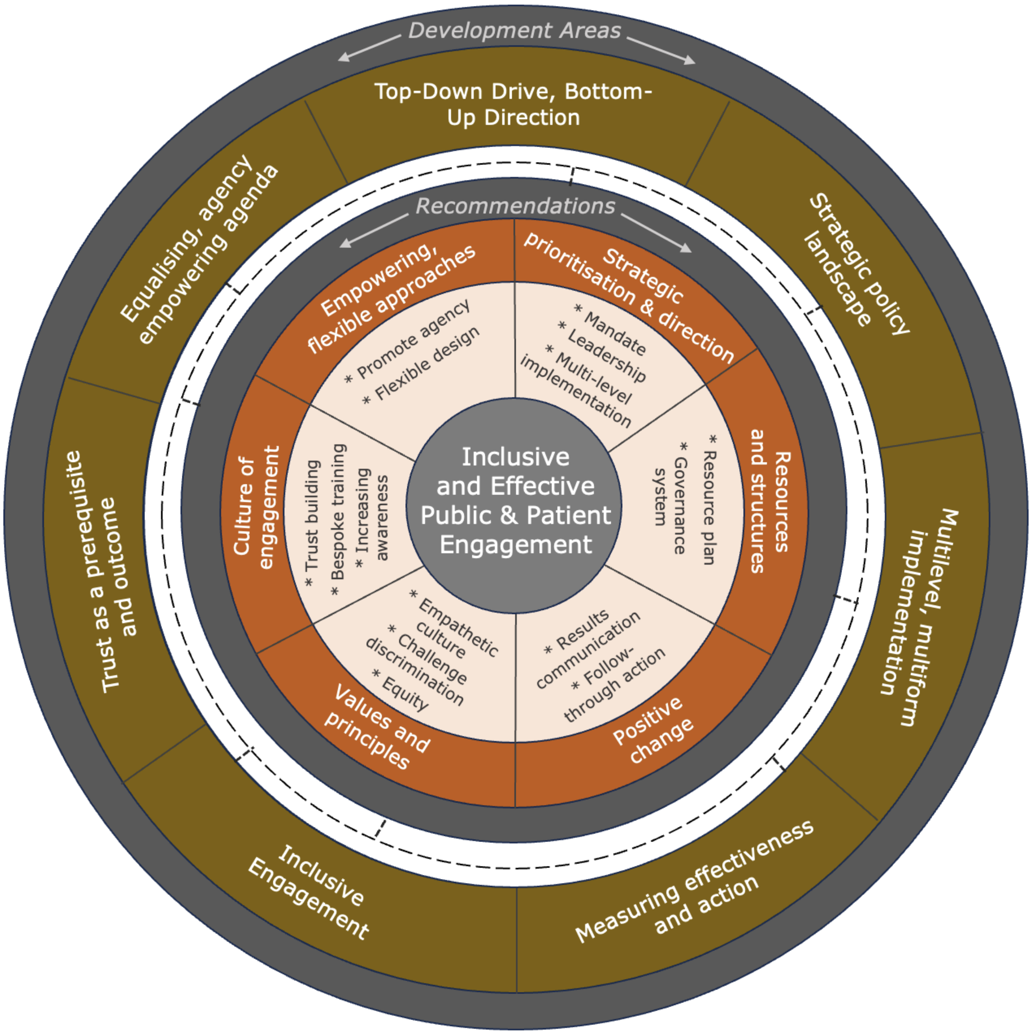

Figure 8.1: Inclusive and effective public and patient engagement for the five groups

It is acknowledged that the recommendations may not, and should not, necessarily reflect state-of-the-art trends regarding broader health and social care reform in systems that are both complex and subject to dis-integration. Taking full account of this wider knowledge context is outside the scope and objectives of this work. In the same manner it is also acknowledged that these recommendations have not been interrogated in terms of their operational and budgetary feasibility, or compared and assessed against the legacy of historical, and sometimes unsuccessful, efforts at implementing solutions. This needs to be the focus of future work.

With reference to figure 8.1, the recommendations cut across the seven areas of development, and can be broken into six broad categories. The recommendations are designed to nurture a multi-level system approach that should enhance integration and coordination across engagement activities for these groups, while also allowing for the need for discrete leadership, implementation and action at each level of the health and social care system. Practical actions are suggested for each recommendation to assist in their operationalisation.

Securing strategic prioritisation and direction

1. A ***specific commitment and mandate*** for public and patient engagement for all five populations is still required and must be given by HSE national management for valuing, prioritising, and implementing service involvement for these groups.

   Action 1.1 Ensure related policy, and implementation plans and resources, at national and regional levels feature this commitment and mandate.

   Action 1.2 Assess and operationalise current and future public and patient engagement frameworks in collaboration with the five populations, defining the scope and scale of involvement for these groups.

2. ***Leadership at strategic and operational levels*** of the health and social care system must be established to drive and embed public and patient engagement for the five populations. It must also be based on a collaboratively determined agenda with the groups that links to other national, regional and local priorities.

   Action 2.1 The HSE and the Department of Health to jointly establish a national strategic direction, and define who has responsibility for leading engagement in their respective divisions for these groups.

   Action 2.2 Health Regions to embed regional leadership for engagement with the five groups, and support local provider networks in developing organisational-level plans for general engagement activity and peer work roles.

3. A ***multi-level implementation programme*** for public and patient engagement, which is impact-orientated and integrated, must be executed by the HSE and its Health Regions for the five groups. It must be developed in partnership with those with lived experience, and supported by a defined and appropriate resource allocation that drives action.

Action 3.1	Integrate lived experience views in national level decision making, with respect to service planning, resource allocation and policy formation.
Action 3.2	Implement public and patient engagement structures and activities for these groups in Health Regions, including within service teams and programmes.
Action 3.3	Service providers to review their organisational/unit and service processes to identify opportunities and execute action-orientated engagement.

Establishing critical resources and structures

4. A comprehensive ***resource plan*** is required to ensure that public and patient engagement for these groups is embedded at all operational levels of the care system, across budgets, staffing, training and development, evaluation and, critically, follow-on actions.

Action 4.1	Increase workforce numbers dedicated to engagement with these groups (through new roles or staff reallocation) within national HSE offices, Health Regions and provider organisations to support awareness building and activities.
Action 4.2	Financially support the investment of local community, and representative organisations in amplifying lived experience perspectives, helping to sustain the engagement of individuals from these communities over time.

5. Public and patient engagement for the five groups must be underpinned by a ***clear system of governance***, which establishes multilevel oversight and responsibility, and secures accountability at HSE national, regional, and local cross-sector organisation levels.

Action 5.1	Establish governance at each level that sets out operational space, prioritisation, and responsibility for these groups' involvement in services.
Action 5.2	Embed lived-experience perspectives within governance structures at each level, helping to ensure equity and fairness in governance processes.

Generating and sustaining positive change

6. At all levels of the health and social care system, public and patient engagement processes must work to ***drive follow-through action*** and transformative change. This includes leveraging resources and action, and pursuing targets and outcomes related to better services and health, and greater empowerment and inclusion, for the five groups.

Action 6.1	Establish monitoring and evaluation structures at all system levels that foster evidence-informed review and high-quality engagement, targeting impact.

Action 6.2 Set key performance indicators at all levels of the care system to assess engagement processes, outcomes, and longer-term changes, tying resource allocation to effectiveness, and reinforcing a culture of accountability.

7. The ***communication of the results of actions*** arising from engagement activities to all those involved must be completed in a timely manner to demonstrate transparency, trust, and follow-through, and to identify successes, failures, and other outcomes.

   Action 7.1 Keep engagement participants connected and up dated in relation to on-going activities, efforts to implement actions and key outcomes.

   Action 7.2 Invest in and promote potential best practice examples that help to communicate, inspire and illustrate success, and generate impetus with respect to the importance and relevance of engagement for the five groups.

Setting values and principles

8. ***Equity*** must be instituted as a core value in involvement for the five groups, ensuring that public and patient engagement helps to equalise power within the co-production of services and polices at regional and national levels, and in individual service exchanges.

   Action 8.1 Ensure respect for individual, group, and intersectional identities is built into all engagement activities with these groups, in terms of ethos and materials.

   Action 8.2 Recognise and incorporate individual and group diversity within engagement at all levels, supporting representative voice and countering homogenisation.

9. Public and patient engagement must be embraced at all policy and operational levels as a means to ***challenge discrimination*** that can be encountered by members of the five populations within the health and social care system.

   Action 9.1 Public bodies to adopt engagement approaches in support of their Public Sector Equality and Human Rights Duty to assess, address and report on rights and equality issues related to these groups.

   Action 9.2 Service organisations and people with lived experience to use engagement activities to identify potential discriminatory mechanisms and instances.

10. Public and patient engagement implementation must help engender an ***empathetic and collaborative culture*** within the health and social care system, nurturing and setting ambitions for these populations that combat societal-, system and self-limiting beliefs.

    Action 10.1 Develop engagement activities that help elevate expectations of what can be achieved in health, recovery, and social inclusion domains for the groups.

    Action 10.2 Implement engagement in a manner that reflects, and supports intercultural understanding and humility with Traveller, migrant, and minority groups.

Enabling a culture of engagement

11. ***Trust building*** should underlie public and patient engagement for the five population groups, where there is a need to nurture trusting relationships in engagement, and where processes should more widely enhance trust in the health and social care system.

    Action 11.1 Set clear parameters around privacy, use of information and intended action arising from engagement activities in the early stages of the process.

    Action 11.2 Work to establish trust in the health and social care system as a measurable goal or by-product of engagement processes.

12. ***Bespoke staff training***, which is informed by a lived-experience perspective, and tailored to the engagement needs of the individual groups, must be mandated by the HSE, and must be the responsibility of each individual Health Region, and their network of service organisations.

    Action 12.1 Assess and address staff training needs regarding engagement with these groups at national, regional and local provider levels.

    Action 12.2 Build trauma-informed approaches that are sensitive to the life-course experiences of individuals and groups and supported by shared learning resources (tool-kits; manuals) coproduced by the HSE with the groups.

13. ***Increasing awareness*** of public and patient engagement and its importance amongst the five population groups must be central within future efforts within this area – particularly for those who are less connected with formal systems and service.

    Action 13.1 Establish accessible HSE-led public campaigns, and targeted promotion activities for each of the individual population groups.

    Action 13.2 Develop creative processes for motivating engagement, including those that are relevant to different and less connected sub-groups (age; gender, etc.).

Empowering and flexible approaches

14. Public and patient engagement of all forms must promote the ***individual and collective agency*** of these groups, where organisations/units tasked with implementation must ensure that there are ancillary processes that empower this agency within the engagement process.

    Action 14.1 Facilitate small group and one-to-one orientation sessions to alleviate anxieties and concerns of lived experience participants ahead of engagement.

    Action 14.2 Deliver training and capacity building locally to increase knowledge and familiarity of engagement. Provide short modules, coproduced with the groups, and representative and adult learning agencies.

15. Public and patient engagement methods for the five populations should be based on a ***flexible design*** to support person and group-centred involvement and coproduction, and must be selected and adapted in collaboration with representatives of the target audience.

Action 15.1	Implement engagement processes that use methods tailored to people's preferences and approaches inclusive of their circumstances and capacities.
Action 15.2	HSE to work in collaboration with the National Adult Literacy Agency to ensure that the language and communication around engagement is in line with the 10-year adult literacy, numeracy and digital literacy plan.
Action 15.3	Conduct a periodic appraisal of the accessibility and appropriateness of engagement activities, spanning physical, social, and cultural dimensions.

8.3 Concluding Remarks

As a central contribution of this research study, this report has for the first time analysed the current state of public and patient and engagement for the five populations, drawing out what service involvement means and what challenges need to be overcome for these groups. Critically, in identifying the key areas of development and the 15 supporting recommendations, this report presents a research-informed strategy for operationalising inclusive and effective public and patient engagement for the five populations.

The findings reflect what other international research studies and reviews, as well as smaller-scale local projects in Ireland, have previously documented and identified. The findings can also be considered to reflect the necessary components of Public and Patient Engagement outlined within the HSE Better Together Roadmap (HSE, 2023). However, missing from the Roadmap – and understandably perhaps given its operational focus – is a sufficient emphasis on counter actions to address more innate system and structural issues that impede the strategic direction, governance, and cultural openness needed for effective service involvement for these five populations. Certainly, this to some extent relates as much to public and patient engagement in general, with all those who use health and social care services, as it does to the five groups. Nevertheless, the force and embeddedness of these impediments is particularly pronounced and damaging for the populations in this study. Engagement related system and structural issues intersect with challenges that have traditionally contributed to unequal service access and delivery for the five groups.

Notwithstanding the limitations of the research, a key part of this study has been to isolate these shared challenges, and to point to common elements of a more inclusive and effective pathway to engagement in health and social care services. These circumstances should be recognised and should be addressed. Otherwise, there is a danger that public and patient engagement will lose traction, will be perceived as meaningless, and will become more of a destructive than constructive force for individual and group agency. It is also important to recognise that not all members of these groups will want to engage beyond that of their individual service and supports. Such a preference might be motivated by past negative experiences, a more cynical or dissenting view of engagement activities, or just individual choice. Regardless, this agency must be respected and not problematised or viewed as complacency towards service quality or personal well-being. While public and patient engagement should be encouraged for the five populations, with opportunities created and offered, framing these activities as a normative expected practice is likely to disempower rather than support individuals and groups within these populations. This would be a failing of our engagement culture and process, and not of individual members of these groups.

Reflecting the consensus view of the majority of informants in this study, national stakeholders, service providers and lived experience participants were clear about the potential of engagement and were hopeful in terms of its future impact. Throughout this work there was a collective will to elevate the position of individuals and groups in these populations as contributors to, and leaders of, their health and social care services. Public and patient engagement was in overall terms seen as a powerful means of realising that will, and of fostering a recognition of the agency of individuals and groups. It is critical that this collective will is appropriately supported for these groups. Otherwise, those most in need, will remain outside of the system. In doing so, there are likely to be ethical and social inclusion gains, but also gains in terms of system efficiency and system financing, where services are more likely to be effective and cycles of treatment and support more impactful.

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Appendices

Appendix 1A: Study Steering Committee

John Healy	Genio Trust
Louise Conlon	Genio Trust
Marieke Altena	HSE National Social Inclusion Office
Michael Ryan	HSE Mental Health Engagement & Recovery Office
Ruth Armstrong	HSE National Social Inclusion Office
Nicola Corrigan	HSE National Social Inclusion Office
Caro Theunisz	HSE National Social Inclusion Office
Brigid Quirke	HSE National Social Inclusion Office

Appendix 1B: Project Advisory Board Membership

Sarah Morton	University College Dublin
Diarmuid O'Donovan	Queen’s University Belfast
Oliver Cullen	Recovery College South East
Chris O’Donnell	SafetyNet Primary Care
Osas Iyamu Usideme	Waterford and South Tipperary Community Health Service
Nicholas Jose Diez McKenna	UISCE
Cliona Ni Cheallaigh	St. James’ Hospital/Trinity College Dublin
Mary Brigid Collins	Pavee Point
Funders and Collaborators	
John Healy	Genio Trust
Louise Conlon	Genio Trust
Tara Doheny	Genio Trust
Marieke Altena	HSE National Social Inclusion Office
Michael Ryan	HSE Mental Health Engagement & Recovery Office
Ruth Armstrong	HSE National Social Inclusion Office
Nicola Corrigan	HSE National Social Inclusion Office
Caro Theunisz	HSE National Social Inclusion Office
Brigid Quirke	HSE National Social Inclusion Office
Joe Doyle	Health Service Executive National Social Inclusion Office

Appendix 1C: Advisory Group Terms of Reference

1.0 Purpose

The following Terms of Reference set out the composition and governance structures to guide the work of the Advisory Group as it relates to the research being conducted by the National University of Ireland Galway (NUIG). The study has been commissioned through NUIG and will seek to investigate the views and experiences of key stakeholders regarding service user engagement across HSE Social Inclusion and Mental Health services and service users falling under, Homeless health, Traveller health, Migrant and Roma health, Addiction, DSGBV and Mental Health. As such, the Advisory Group will act in a supportive and consultative role, providing guidance to key areas of the study.

1.1 Principal Responsibilities of Advisory Group

The main purpose of this work is to inform practice and to develop approaches to involving lived experience in shaping services in each of the areas. While it is envisaged that NUIG and the Steering Group will retain ultimate responsibility for decision making regarding the study approach, the Advisory Group will act in a supportive and consultative role to inform decisions.

To facilitate this, the Advisory Group will work to:

- Inform the specific focus of the research and provide expert advice
- Guide how the research can be most relevant to practice and align with future service developments
- Broker access to relevant stakeholders in each field across Social Inclusion
- Schedule meetings and disseminate relevant reports/outputs
- Actively participate in meetings through attendance, discussion, and review of minutes, papers and other Advisory Group documents.

The Advisory Group will use a consensus approach to formulate recommendations (a majority approve a given course of action, but that the minority agrees to go along with the course of action, potentially with some modifications).

1.2 Composition and Membership

The Advisory Group has been established as the main arena to advise the direction of the study being conducted by NUIG. The Advisory Group shall have members from key stakeholders across the portfolio of HSE Social Inclusion programmes involved in the study. In addition, members of HSE Mental Health, Genio, academics with relevant expertise and those with lived experience or academics with lived experience will also be included in the Advisory Group. A smaller steering group compiled of HSE Social Inclusion, HSE Mental Health and Genio will manage the contractual obligations between NUIG and Genio/HSE Social Inclusion/HSE Mental Health with NUIG.

1.2.1 The Advisory Group Structure

- Chair: NUIG/Genio
- Secretary: NUIG/Genio

1.2.2 Membership Representatives

See appendix 1B.

1.3 Relationship to other committees

Should there be a need to communicate pertinent issues from the project steering group to the Advisory Group, then structures and means of achieving this should be put in place by the Chair/s.

1.4 Administrative Support

Genio/NUIG will act as Secretary providing administrative support, including compiling minutes of meetings, booking meetings, sending out agendas, and any reports and outputs to be disseminated prior to the meeting (1 week in advance).

1.5 Meeting frequency and location

The time frame for the study is 24 months. As such, the Advisory Group will need to be in place for this period. The full Advisory Group will meet maximum once every three months and the Steering Group will meet initially every three weeks, and thereafter as required for key decisions to facilitate the advancement of the project. Meetings will last 1 hour and 30 minutes. Given the current public health issues with COVID-19, and the dispersed locations of stakeholders, meetings will be held on a communication platform such as Zoom or Microsoft Teams. Meeting dates will be scheduled in advance for the year.

1.6 Term

The Advisory Group will conclude its work when the research is completed, and all outputs have been disseminated.

Appendix 2A – Service provider survey respondent profile

As anticipated, there was substantial overlap in the populations served by service providers. **Error! Reference source not found.**.1 presents the number of organisations that provide services to each population based on this self-report data and is broadly in line with anecdotal information regarding the relative number of service providers working with each group. Although this breakdown is likely to be an accurate reflection of *all* those who may have used the services of these organisations, on closer review it appeared to mask the core group targeted by many of the organisations and dilutes the functions and scope of the organisations. For example, many homeless housing charities would understandably include those with mental health challenges and those from migrant and minority backgrounds within the populations they serve. For this reason, it was the sub-sample of organisations that respond to each of the population specific survey links that was used as the *provider population group* identifier within the survey analysis. General profile information for survey respondents and their organisations is presented in Box 2.1

Populations Served	
Mental health	184
Homeless	142
Migrant, minority ethnic, Roma	103
Travellers	90
Drugs and alcohol	201
General population	79

Table 2A.1: Number of respondents who say their organisation or unit serves each of the populations

BOX 2.1: Profiles of Survey Respondents and their organisation

- The largest proportion of respondents' organisations or units were in Dublin City (44%), followed by those based in 'a town' (31%), and those 'in a city other than Dublin' (18%). Just 7 per cent of respondents' organisations or units were in a village or countryside area.
- The largest proportion of organisations were small in size with fewer than 20 personnel (42%), while nineteen per cent had 21-50 personnel in their organisations and 16 per cent were from organisations with 101-500 personnel.
- Under half of respondents' organisations (44%) were voluntary or community based. Slightly fewer (37%) were public sector organisations (including but not limited to hospitals or health institutions), while nineteen per cent described themselves as being from non-Governmental organisations.
- In identifying all the sorts of services their organisations provided, most respondents' organisations provided health, mental health, and/or social care services (37%, 43% and 45% respectively). Twenty-eight per cent provided services linked to community development and slightly fewer did work in relation to advocacy (25%).
- In identifying *all* the roles they held within their organisation, 52 per cent of survey respondents reported having responsibility for the design or delivery of services, forty-seven per cent reporting having a role in service involvement coordination, and just less

than a third (32%) reported having responsibility for organisational policy or strategy for service involvement.

- Eighty-eight per cent of respondents reported having either ‘good’ or ‘very good’ knowledge around service involvement, and eighty-five per cent said their knowledge of policies, documents, or guidelines relevant to service involvement was ‘good’ or ‘very good’.
- Thirty-seven per cent of respondents had up to six years’ experience in service involvement. Thirty-six per cent had more than 14 years' experience, and twenty-seven per cent had between seven- and 14- years’ experience in the area.
- Those with direct responsibility for service involvement were much more likely to report good knowledge around service involvement and its policies and a longer duration of working in service involvement.

Appendix 3A: Service involvement in health and social care services

This section presents a review of the general literature pertaining to service involvement in health and social care services. This section charts the overall development and main pillars of service involvement, provides an overview of models of involvement in different national health systems, outlines the critiques of that involvement, and presents some illustrative examples of specific involvement models and measures.

3A.1 The development and main pillars of service involvement

There is widespread and growing interest in supporting the involvement of those with lived experience in health and social care services, policy and research (Erikson, 2018; Beresford, 2019; HSE, 2020; Ocloo et al., 2021). In general, service involvement in the broadest sense is understood as emphasising a move away from service-led systems to those which centre on the individuals or communities who use the service, and the contribution they can make in shaping service policy, planning, governance, and delivery (Bombard et al., 2018; McEvoy et al., 2019; McMillan, 2019). In the context of health and social care, service involvement is typically considered to be associated with the aim of producing transformative change.

Service involvement can take multiple forms involving different degrees of power-sharing on a continuum from once-off participation, such as in health consultation events, to medium-term initiatives, to more sustained and longer-term embedded partnerships (De Freitas, 2017). It can occur at different levels, including at the level of the individual, at the level of service development and delivery, and at the strategic system or policy level (McMillan, 2019) – with the latter generally viewed as being the least developed (McEvoy et al., 2019). In the context of the Irish health and social care system, the use of the term service (user) involvement reflects these different forms and levels, and is described as involving: *"A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing polices, in planning, developing and delivering services and in taking action to achieve change"* (DoHC and HSE, 2008, p.6, cited in HSE, 2010). A classification used by some researchers to distinguish between different types of involvement includes 'choice', 'voice' and 'co-production', where these terms reflect 'consumerist', 'deliberative' and 'participative' involvement respectively (Andreassen, 2018).

Involvement terminology is often judged to be too broad, where a lack of clarity can contribute to misunderstandings of expectations and goals between different groups of stakeholders, creating barriers to productive involvement (Tierney et al., 2016; Andreassen, 2018). Service involvement, therefore, is called by several names within health and social care, including participation, engagement, patient centredness, patient experience, patient activation, shared decision making, relationship-centred care, patient- and family-centred care and peer involvement (Carman et al., 2013; Batalden et al., 2016; Tierney et al., 2016; Higgins et al., 2017). Mindful that it is difficult to draw clear boundaries between these different sets of terminology (and related approaches), it is possible to identify major areas of development which have informed contemporary understandings of service involvement. This includes work related to participation, encompassing public and patient engagement and involvement, and co-production and related co-form activities.

3A.1.1 Participation with public and patients

Participation may be conceived as a global vision demonstrating a common goal of inclusivity for those who use services in the health and social care system, where empowerment and partnership are deemed central (Halabi et al., 2020). As well as including individuals and communities in health and social care services, structures and policies (De Freitas, 2017; McEvoy et al., 2019; McMillan, 2019), participation is understood to involve the redistribution of power in order to enable those who use services to bring about reform. This might, for example, be in terms of determining how programs are operated or how goals and policies are set. Arnstein's (1969) seminal guide for participation, the *'Ladder of Citizen Participation',* stipulates that those involved should have real power, as opposed to participation being an empty gesture. This principal was asserted again when in 1978 the World Health Organisation noted people's right to participate in the planning and implementation of their care (WHO, 1978; De Freitas, 2017). However, Beresford (2019; 2020) problematises Arnstein's perspective, pointing to the essentially political nature of participation that is not addressed in this conception. Participation in health and social care is influenced by social and public policy from which those who use services have historically been excluded (Beresford, 2019; Mulvale et al., 2019; Snow, 2022). Therefore, participation must be understood in broader ideas and practices of democratisation (Beresford, 2019).

Public and public involvement (PPI) and public and patient engagement (PPE) are together considered to be integral to this longer participation tradition of involvement. The emergence of Public and patient involvement (PPI) can be traced back to the UK in the 1970s, but is now viewed as being international in nature (Beresford, 2019; Ocloo et al., 2021). Depending on what part of the world research on PPI or PPE arises from, one or the other term may be favoured, with generally both derivatives being used in reference to or contributing to a common set of practices (Gallivan et al., 2012). Ocloo et al. (2021) describe PPI as premised on the principle of involving those who use services in research, delivery and improvement in health and social care systems. Cluley et al. (2022) note the lack of a universal contemporary definition of PPI, but adapt existing descriptions to delineate it *"as an 'active partnership' between members of the public, patients and those supporting innovation in healthcare"* (p. 841). Similarly, Carman et al., (2013) describe PPE as corresponding to micro (direct care), meso (organisational design) and macro (policy making) levels, as well as relating to the 'depth' of participation, from consultation to partnership and shared leadership. Patient and Public Involvement and Engagement have thus evolved to encompass a wide range of involvement activities. However, they have also developed to emphasise more meaningful in-depth forms of service involvement, that encompass partnership forms of production (Gallivan et al., 2012; Barello et al., 2014; Higgins et al., 2017; Majid and Gagliardi, 2019; Halabi et al., 2020; HSE, 2020; Usher and Denis, 2022). The focus has expanded from engagement in disease management, to engagement in issues of quality and safety, to ideas of value and co-production (see next section) (Usher and Denis, 2022).

As demonstrated in the slippage of terms and the overlap in definitions, there is not always clarity regarding what public and patient involvement and engagement is and how it should be operationalised. Current challenges include the lack of a common language, underexplored issues of power imbalances between staff and those who use services, a lack of representation in involvement activities, and a lack of evidence about how equitable practices might be replicated (Ocloo et al., 2021). The issue of how undertakings at different levels interact within and beyond the individual care and provider institution realms is also not well investigated (Usher and Denis, 2022). There are calls to understand how engagement is translated into outcomes achieving the transformative expectations of collaborative health (De Weger et al., 2019). Reviews of work in this area have similarly pointed to a lack of evidence of impact on the implementation of innovations (Brett et al., 2014; Cluley et al., 2022).

3A.1.2 Co-production and related strategies

Co-production and the family of co-form strategies are typically considered to refer to the more involved, targeted, and collaborative forms of service involvement. However, some researchers argue that while co-production may generally vary in the degree of shared decision-making from public and patient involvement and engagement, is not essentially that different (Hughes and Duffy, 2018). Building on earlier work relating to citizen and healthcare professional dynamics, co-production entails individuals as well as communities holding equal power with service providers and professionals in the planning and implementation of a service or product (Slay and Stephens, 2013; Palumbo, 2016; McMillan, 2019; Fusco et al., 2020). Filipe et al. (2017) propose a broad understanding of co-production as an exploratory space to generate different ways of thinking that can lead to new forms of knowledge, values, and social relations with the potential to influence health and social care. The expected benefits of co-production include service improvement, greater sustainability of the health and social care system, more efficient use of resources, potentially increased satisfaction levels of citizens, and improved individual/provider relationships (Palumbo, 2016).

Like public and patient involvement and engagement, Slay and Stephens (2013) highlight how co-production conceptualises different levels of involvement, incorporating ‘doing to’, where individuals are not participants; ‘doing for’, where individuals are invited to be heard; and ‘doing with’, where individuals and services work together equally – with the latter representing the most advanced in shifting power towards people (Slay and Stephens, 2013). At this level, fundamental change is necessary in how providers work with those who use services, moving to equal and reciprocal relationships. Again, like the other concepts, the literature on co-production identifies three levels of operation, including: the macro level, involving co-governance for achieving improved health services; the meso level, where health interventions are planned and designed; and the micro level, involving the one-to-one relationship and the inclusion of individuals in their health care provision (Palumbo, 2016).

A range of other co-form strategies have also emerged within the broad area of service involvement and public services. Again, terminology referring to these strategies has often been used interchangeably with the co-production concept (Vargas et al., 2022). This is particularly the case with co-creation. While some researchers consider co-production as an aspect of co-creation, others consider co-creation as involvement *“in the initiation or design of public services”* and, more recently, as value creation through the interactive relationship between the public service organisation and participants with lived experience (Voorberg et al., 2015, p.366; Osborne, 2018). Khine et al. (2021), investigating research trends and conceptual approaches in the field, highlight that co-production is related to services at implementation level while co-creation is associated with the strategic level and occurs at an earlier stage. Similarly, co-design is generally taken to refer to a collective form of creativity across the design process, rather than being directed towards implementation or delivery stages (Masterson et al., 2022). In an attempt to reconcile some of the differences and overlaps, Vargas et al. (2022) presented co-creation as an overarching concept that includes co-design and co-production. The authors define co-creation as the active involvement of stakeholders, from the exploration of problems and the identification of needs through to the creation, implementation, and evaluation of solutions.

Several of the other challenges observed with respect to public and patient involvement and engagement have also been found in relation to co-production and the co-form approaches. Issues of equality, representation and power imbalances require further research, along with the need for further evidence of scaled up and evaluated outcomes. Studies have also noted that there can be a failure to outline specific objectives in studies involving co-production, which suggests an assumption that involvement in this way is considered to be a virtue in itself (Voorberg et al., 2015). Research tends to focus on experimental initiatives rather than practices and governance reforms (Usher and Denis, 2022). A central challenge is to develop theories of how health care services should learn from and change or adapt to operationalise co-production into new policies and models of administration.

3A.1.3 Current state of knowledge

Despite the growth of interest surrounding service involvement in health and social care, many researchers stress that this should not be automatically taken to mean progress. Beresford (2019), for example, suggests that there is in overall terms a lack of advancement in the development of involvement as a practice field – noting the need for common language and clearer conceptualisations, and the fragmented nature of empirical work on this topic. As referenced in the previous sections, there is a lack of evidence on costs, social return, impacts on health and wellbeing, and the long-term effects of participation on those who use services. That said, there is a growing evidence base related to the efficacy of peer work and its impact on service improvement and service delivery (Kotera et al., 2023; Lyons et al., 2021). Nevertheless, it is argued that these deficits need to be addressed before the potential of service involvement can be fully realised (McMillan, 2019). Within the field of co-production, there is more empirical evidence on knowledge co-production and service co-design than on co-delivery and co-management, which are considered to be at a more theoretical stage (Fusco et al., 2020). Evidence that explicitly draws out the impacts of co-production for people who use services and service providers is generally under-developed (Fusco et al., 2020). However, where inclusion initiatives are followed to fruition in the form of co-production and co-creation models for health and social care service implementation, benefits have been noted to accrue in services, systems, and policies (Micsinszki et al., 2022; Roura et al., 2021). Of particular relevance to this study, there is little consolidated knowledge about how the organisation of health and social care services should incorporate involvement in the design, delivery and evaluation of a work practice, or how organisations can integrate and sustain service involvement initiatives.

3A.2 Models of involvement in national health and social care systems

Service involvement is, in many cases, at the forefront of health and social care policy agendas internationally (De Freitas, 2017; Andreassen, 2018; HSE, 2020). Reflecting the range of related activities, country systems operate at different points across the continuum of involvement, from once-off participation to shared leadership, as they seek to achieve their goals and priorities (Marston et al., 2016). For example, in Brazil, involvement in developing health care policy is a constitutional right and is expressly enshrined within its legislative system; in the Netherlands, the responsibility for involvement lies typically at the operational level of health and social care services; whereas in Canada, involvement is seen at multiple levels across health and social care policy and practice (De Freitas, 2017). In France and Germany, the legal context obliges healthcare professionals to respond to the shared decision-making rights of those who use services. In the UK, shared decision making is firmly on the policy agenda, and can be seen within commitments from policymakers, professional and patient organisations and the courts. Whereas in the US, state and federal initiatives have connected such rights with reimbursement and protection from litigation (Härter et al., 2017).

Returning to the different underpinning philosophies of involvement, the rhetoric of involvement within health and social care systems can be driven by distinct consumerist (choice), deliberative (voice) and participative (co-production) models of involvement (Andreassen, 2018) – with the first conceived as managerialist and the latter two as democratic (Brosnan, 2012; Ocloo and Fulop, 2012). While these models have been linked with influencing different types of engagement in different national health and social care systems, it should be noted that in practice this may not always be clear cut (Tritter and McCallum, 2006). For instance, in Norway and the UK there is a dominant model of democratic involvement (seen in advisory bodies comprised of those who use services in Norway, and public panels in the UK). Swedish public policy draws on both a democratic and managerialist approach, moving from the self-mobilisation of those who use services, towards their activation in organisations' internal evaluations, development, and quality management (Eriksson, 2018). In the case of Finland, which is relatively new to the development of service involvement programmes, the consumer role of the citizen is strongly present, and there is growing concern, as elsewhere, of the diminishing power of representative democracy to influence public affairs (Jones and Pietilä, 2017; Rantamäki, 2017).

In terms of assessing the outcomes of service involvement strategies at a national or regional systems level, again, the research available is limited and rarely moves beyond studies and microsystem settings (Persson et al., 2021). There are nevertheless some recent exceptions. In Sweden, within the Region Jonkoping Health System, co-production initiatives at different levels evolved as a significant aspect of services, with a focus on developing new ways of working (Persson et al., 2021). Outcomes included increased patient autonomy and reduced need for health care. Some concerns were raised by healthcare professionals regarding patients having greater responsibility for treatment. However, attitudes tended to shift over time to recognise the competencies and skills of those involved. The main lessons learned included the need for better evaluation capacity, the importance of engaged leaders and healthcare experts, harnessing a strategy for improvement, consistency of direction, and continuous learning from experience (Persson et al., 2021).

A study of community engagement approaches in the Dutch healthcare system found that healthcare providers and those who use services differed in how they defined and experienced engagement (De Weger et al., 2020). The researchers recommend that community engagement can be improved through establishing a shared and overarching vision, clear roles for organisations and communities, structured representation, and training for health professionals. A review of the impact of service involvement within the UK National Health Service found a range of positive impacts. But a lack of detailed evidence, a theoretical underpinning, a defined measurement approach and an analysis of costs meant that these impacts were difficult to truly assess (Mockford et al., 2012). However, in a study of intervention tools to improve the management of medicines in care transitions in the UK, Raynor et al. (2020) found that lived experience-based co-design *"can be successfully adapted for use across an entire patient pathway with multiple organisations and between health economies"* as a valuable approach to improve services (p.568).

In summary, while some advances are demonstrated across national health and care systems with respect to the integration of service involvement, the gaps between aspirations and reality remain significant. Across contexts there is a need for underlying evidence demonstrating experiences and expectations of involvement, and programmes evaluating the impact of interventions (Härter et al., 2017).

3A.3 Critiques of Involvement Practices

Setting aside some of the challenges with respect to service involvement already described, a number of more fundamental critiques of involvement strategies have also emerged. These are typically concentrated within the theoretical and review literature, and while they focus on more involved forms of service involvement, such as co-production, they have relevance to a range of activities and other areas of work. Existing critiques also contextualise and underlie many of the more practical challenges described later in the review.

First, researchers have noted that risks can arise from the ways in which service involvement can contradict dominant public sector institutional structures and processes. This is particularly highlighted where involvement occurs within a landscape where *"regular producers"* often wish to retain control over service delivery (Palumbo and Manesh, 2021). These risks, which are in themselves recognised as reflecting the innovation of such processes, are considered to be rarely countered by risk-reduction strategies. This can frustrate service involvement strategies, limiting the positive outcomes that can be achieved (Williams et al., 2020). It has also led some researchers to identify the overall limited nature of involvement and to suggest that these processes can be *"time-consuming, ethically complex, emotionally demanding, inherently unstable, vulnerable to external shocks, subject to competing demands and [...] challenges many disciplinary norms"* (Flinders et al., 2016, 261).

A review exploring service involvement among people in vulnerable situations found that while involvement can facilitate empowerment for those who use services, it can also result in disempowerment. The researchers recommend that in facilitating involvement, service providers must consider the possible harm the processes may cause (Gathen et al., 2022). A review of citizen involvement in public services found that the negative side-effects of co-production on public values can include unfair and unequal access to public services, and a risk of the contamination of public services with private interests (Palumbo and Manesh, 2021). If not supported by actions to mitigate discrimination and inequality of participation, it is possible that *"co-contamination"* will arise as the *"the dark side of co-production"* because of the misuse of service provider or citizen resources. This may occur accidentally, due to a lack of training for participants, or intentionally when those in authority abuse their power (Williams, Kang and Johnson, 2016). Contamination issues are especially challenging in virtual spaces, as these forms of involvement may trigger discrimination and favour already privileged groups, undermining the very purpose of collaborative techniques (Palumbo and Manesh, 2021).

By and large the *dark side* critiques, however, do not emphasise the failure of involvement and co-production strategies themselves, but instead the factors that hamper the development of productive processes (Williams et al., 2016; Williams et al., 2020). As such, Palumbo and Manesh (2021) propose a service blueprinting approach to accommodate *'public service logic'* in providing for positive co-production. So as to bypass provider-led service delivery models, the blueprint involves enhanced preparedness for meaningful involvement and a three-strand transformation of structures and management techniques (Wood, 2016; Farr, 2018; Palumbo and Manesh, 2021). First, a multi-layered mechanism for co-production involving flexible approaches is suggested to provide for the expression of diverging needs and expectations (Park, 2020a). Second, greater representativeness in the public service workforce is offered to foster trust and positive exchanges with citizens (Riccucci and Van Ryzin, 2017). Third, decentralisation is identified as helping to streamline involvement processes, particularly for excluded populations, to allow for more flexible models of co-production (Palumbo and Manesh, 2021). Palumbo (2016) states that as well as structural changes, behavioural changes through training and support are needed to equip citizens with engagement competencies, and to empower regular service producers to acknowledge the advantages of co-production.

The COVID-19 pandemic has been found to exacerbate some of the risks associated with service involvement, as well as drawing attention to more engrained long-standing challenges regarding the prioritisation of lived experience. In this regard, a number of authors have noted the missed opportunity to globally advance service involvement during the pandemic, and the urgency to bring inequality issues to the forefront of involvement debates (Richards and Snowcroft, 2020; Clark et al., 2021). The role of community action during the COVID-19 outbreak included containing infection, coping with isolation and helping people to recover. Despite the role of community action, health and social care systems have been slow to recognise the importance of a collaborative approach to tackle the pandemic, based on local health professionals working with communities (Cepiku et al., 2021). Instead, policy commitments to involvement and shared decision making were often abandoned (Richards and Snowcroft, 2020). A scoping review on engagement activities happening in the first six months of the pandemic found a predominance of consultation level strategies, such as virtual consultations in individual care, and the use of technology for information sharing and gathering. There was limited involvement in service improvement, and a lack of examples of genuine partnership in organisational level decision-making (Cadel et al., 2021). An evidence synthesis for COVID-19 prevention and control similarly found little evidence of engagement at decision-making levels, and very little efforts to ensure equity of voice (Gilmore et al., 2020). Many governments and health authorities imposed measures from the top down, with little consideration of the effects on particular communities (Turk, 2021). However, a co-designed COVID-19 uptake programme in the UK targeting populations (the five groups within this study) led to significant engagement and uptake (Berrou et al., 2022). The programme included outreach activities coupled with a co-designed communication and engagement campaign with community leaders. The researchers note that the programme represents a strong foundation for future collaboration. Despite such promising initiatives, however, it is still asserted that service involvement remains seen as non-essential and secondary to traditional expertise (Richards and Snowcroft, 2020).

3A.4 Service Involvement and Representation

As noted in the previous sections, one of the factors impeding successful forms of service involvement is the low level of representation. In this section, issues around general representation are given further consideration.

One of the primary goals of service involvement – to ensure the needs and values of those who use services inform the development of services – has proven particularly challenging to achieve for those often discriminated against and underrepresented in society (Ní Shé et al., 2019; Gathen et al., 2022; Snow, 2022). Significant inequalities and exclusions remain evident within health systems which act as barriers to progress and supporting diversity (O'Donnell et al., 2016; Beresford, 2019, 2020; Ocloo et al., 2021). Such populations, though they are sometimes solicited for symbolic reasons, are less likely to be heard and valued in involvement practices, particularly at higher levels (Ocloo and Matthews, 2016; Ní Shé et al., 2019; Park, 2020a; Snow, 2022). Involvement is undermined when barriers disempower some groups who already face discrimination in society, including on the basis of ethnicity, where people live, or if they are seen as problematic or unwanted voices (Ocloo and Matthews, 2016; Mulvale et al., 2019; Beresford, 2019, 2020; Williams et al., 2020). Barriers can involve physical, social, psychological, cultural, or structural factors (Roche et al., 2020; Lourenço et al., 2021). The context and structure of involvement approaches themselves can also be exclusive, without the capacity to cater for the needs and agencies of individuals within seldom heard groups (Snow, 2022). While being included in research to inform service delivery can help ensure involvement initiatives are well tailored to communities' needs, many of these same populations are also often excluded from research (Roche et al., 2020; Amann and Sleigh, 2021; Micsinszki et al., 2022). Moreover, academic and third sector organisations who aim to advance more appropriate strategies have been found to face systematic, cultural, and funding barriers related to discrimination, further disenfranchising the groups facing prejudice (Mulvale et al., 2019; Beresford, 2019, 2020; Williams et al., 2020).

3A.5 Inclusive Models of Involvement

In this section, some illustrative examples of inclusive models and frameworks for including those who can encounter exclusion are described. Although the degree to which research on barriers and facilitators has been developed into tools that have then been applied to service involvement in practice is, in relative terms, limited, some common principles are evident across those models that do exist. These include: a non-hierarchical approach; the empowerment of participants; the need for flexibility on the part of planners; and a recognition that a one size fits all approach does not exist. The models presented here focus on facilitators, gender implications, creativity in combining methods, the use of digital technologies, and the dynamics of power relationships. They demonstrate the interlocking factors – practical supports, values and beliefs, and adaptable strategies – that support service involvement.

Hernandez, Robson and Sampson (2010) develop a practice model to show how populations who are typically seldom heard can be included in involvement to develop services and policies. The model outlines the processes needed to promote involvement and embed it in institutions. It is designed based on findings from a study with four seldom heard groups. The model shows firstly how three key practical conditions are necessary for involvement to occur: sensitivity to participants' circumstances and access needs; organisational support; response to participants' feedback. Next, five factors that foster appropriate values and beliefs are identified: feeling valued through mutual understanding and respect; confidence to (i) get involved and (ii) discuss opinions; belief that involvement will have positive consequences in policy and practice; and a climate that supports involvement. Connectedly, factors that are reactions to practices and activities are described, such as strategies for overcoming constraints, and a range of involvement opportunities.

With reference to Figure 3A.1, De Freitas and Martin (2015) build on Simmons and Birchall's (2005) Participation Chain Model to direct initiatives for involvement of underserved groups. This model focuses on facilitators of involvement and promotes a multi-agency approach involving health authorities and civil society organisations. It is designed based on findings from a case study of involvement in an advocacy project. Illustrating three interconnected sets of factors, the model proposes that incentives to become involved (demand side factors) alone are insufficient without also attending to resources (supply side factors), and additionally nurturing institutional dynamics to generate ability and willingness to participate.

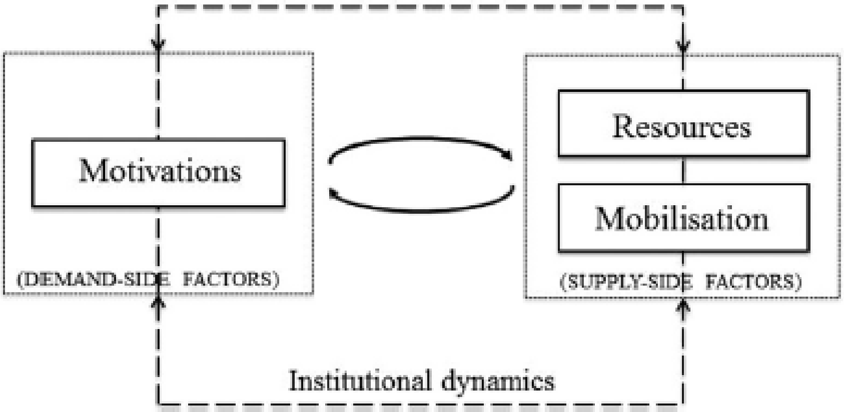

Figure 3A.1 Modified Participation Chain Model (De Freitas and Martin, 2015, 37).

Snow, Tweedie and Pederson (2018) employ a gender lens to help them identify and account for systematic barriers and power dynamics in involvement processes for particular populations. The model seeks to guide planners through these issues as well as supporting them to listen and respond to those with lived experience, as they develop a safe and empowering engagement process. With reference to Figure 3A.2, the tiers of the process include: assessing program leadership's readiness; defining the purpose; identifying target populations; determining involvement environment; developing information sharing processes; considering the benefits for those involved; a lens on how gender shapes experiences; methods for engagement and recruitment; and information feedback and evaluation. A key recommendation is that there is no one strategy for involvement - instead there must be a process of identifying and fitting a method to the participants' circumstances.

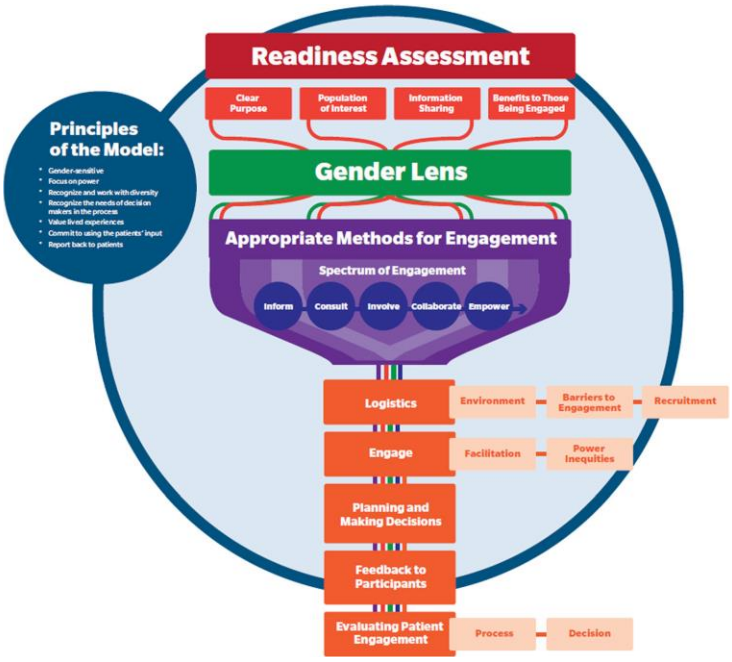

Figure 3A.2 Model of engagement (Snow, Tweedie and Pederson, 2018, p.5)

A number of recent frameworks focus specifically on co-production. For example, Kayser et al. (2018) develop a matrix framework for the co-production of digital services for people who experience exclusion and are living with complex and chronic conditions. Populated with examples from practice, the framework aims to facilitate critical reflection of the design and role of digital technologies for such groups, to mitigate the effects of health service inequity and avoid the creation of an e-health divide among those who may use digital health services. It does so through the use of co-production technology development processes to engage, empower and emancipate these individuals in their interactions with the health system. The framework is suggested to provide a conceptual scaffold across the three inter-related levels of interaction – the individual, the health provider, and the health system.

In reflecting on the models and frameworks presented in this section, it is significant that none have been scaled up across health and social care systems, indicating developments generally remain in their early stages. Connectedly, it is notable that systematic evaluation measures to track the outcomes of involvement for excluded populations have largely been neglected to date.

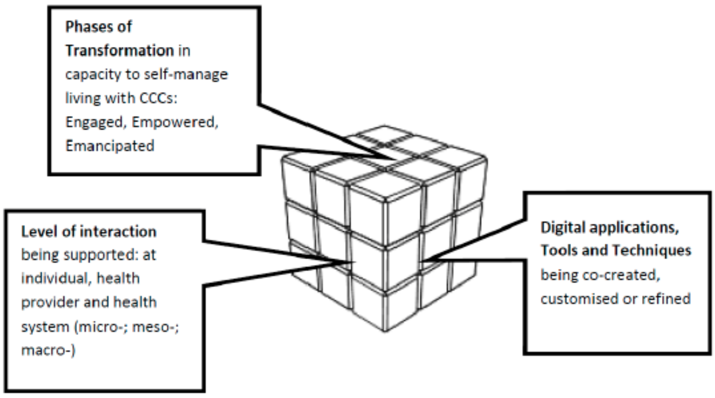

Figure 3A.3 Matrix framework for the co-production of digital health initiatives (Kayser et al., 2018, p.6).

3A.6 Key Messages

1. Service involvement is a multifaceted concept, representing a range of activities that vary in terms of the extent of power given to those who use services in decision-making.
2. More sustained and embedded forms of involvement, at strategic system or policy levels, are generally viewed as being the least developed in practice.
3. There remains a lack of clarity around service involvement, with the conflation of concepts combining with a lack of work on operationalising involvement to create knowledge gaps regarding what is effective.
4. Where involvement initiatives are followed to fruition in the form of co-production models for service implementation, benefits can be observed in services, systems, and policies.
5. While service involvement approaches within different national health systems reflect consumerist, deliberative and participative models to varying degrees, they tend to reproduce similar challenges in terms of addressing power dynamics in engagement.
6. Issues of diversity and inclusion in representation, which can be driven by physical, social, psychological, cultural, and structural factors, remain relatively underexplored within service involvement, resulting in implications and challenges for equitable involvement practices.

7. Consequentially, a critique of the dark side of involvement and co-production has emerged, referring to risks such as abuse of power by those in authority, and the contamination of public services with private interests.
8. Promising developments are demonstrated in inclusive models which, though yet to be upscaled, incorporate work on barriers and facilitators and recognise that a one size fits all approach to involvement does not exist.