'Invisible Minorities': Exploring Improvement Strategies for Social Care Services aimed at Elderly Immigrants in the UK using Co-Design Methods

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This paper forms part of a larger study on how co-design principles can be used in social care service design to mitigate challenges around service use for non-native (immigrant) elders in the UK. Research shows that conventional care for immigrant elders remains fairly inaccessible. Cultural and language barriers ensue a lack of self-confidence, where users would avoid dealing with the state altogether. Often, this user group end up relying heavily on word of mouth and informal family care. This significant absence of independency supports lessened citizen agency, which can negatively impact on the construction of our personal identities. The research aims to use co-design to help foster representation and learning through professional discourse. This method has been proven successful in public projects by encouraging empowerment and belonging within the wider community. A preliminary literature review builds an overview of UK's current social care service structure and a window of insight into the service experience of non-native peoples. Additionally, by dismantling global social care service structures we begin to understand social care best practices, whereas expert interviews reveal the dynamic of organisational culture at local government level and the way in which bureaucratic processes often stump development. By exploring a varied perspective (service designer, user, sociologist), the discussion uncovers opportunity for the development of future service co-design strategies aimed at service providers, that are more culturally sensitive and situation appropriate.

Keywords: elderly; social care; co-design; service design; minority ethnic groups

1   Introduction

The older ethnic population in the UK (those aged 50+) is set to double between 2007 and 2026, from 1.7 million to 3.8 million people (Lievesley, 2010). These comparable changes in demographic and the overall growing number of elderly people in our global societies are expected to be just some of the main social challenges we will face in the coming decades (Zeeb, Rothgang, & Darmann-Finck, 2018). The UK is currently host to the most diverse older populations in the EU. London is home to some of the most varied and largest concentrations, with over 1 million people aged 65+, 22% of which are from ethnic backgrounds and a total of 37% born outside the UK. By 2051 there will be 7.3 million ethnic minority residents in England and Wales aged 50+ (Lievesley, 2010). With this significant

increase, we will care for more people living with multimorbidity and long-term conditions (Ahaddour, van den Branden, & Broeckaert, 2016). As a result, demand on care is predicted to dramatically increase, yet a predicted 26% fewer residents will be in receival of council support (King's Fund Home Truths, 2016). Despite small changes that have recently been developed to consolidate care services around the elderly immigrant user group, almost 70% of them still feel they do not know enough about current care system changes and opportunities (Healthwatch UK, 2018). Among other challenges, a lack of understanding and agency within a service context heightens feelings of anxiety and vulnerability (Anderson et al., 2013). Consequently, due to the limited use of care services by migrant populations, it has been said that institutions are not stimulated enough to offer services tailored to their needs (Ahaddour et al., 2016). As reasons for limited service use are later discussed in this paper, Ebrahim (1996) notes that even when elderly immigrants may make little use of existing services, it must not be taken as an indication of a lack of need. By taking these considerations into account, co-design works by providing a knowledge of existing structures of care, access channels and a sense of working together towards a common goal (Miller & Hamilton, 2008). Overall, this type of community participation strengthens the role of the citizens, which is identity-establishing and is seen as a part of positive community development (Mueller, Lu, Chirkin, Klein, & Schmitt, 2018).

The primary purpose of this paper is to explore how social care services for elderly immigrants are administered, designed and delivered in the UK. Leading to a discussion on some of the challenges within the public service design system and how co-design methods can help improve future development. The nature of this exploratory research requires a qualitative approach using extensive literature review, case studies and expert interviews. This is to form the initial stages of a much larger study, where a framework of co-design principles would be established in order to optimise social care services for this user group.

2   Literature Review

The key areas explored in this literature review are the history and current state of UK social care, as well as ways in which ethnicity impacts service use. Predominantly, this section aims to provide an understanding of how service structures impact access to care.

2.1   Social Care Services in the UK

After the initiation of the 'Welfare State' in 1942, the Beveridge report was the first comprehensive system of social insurance designed to help support the general population out of poverty. Today, the workings of health and social care services in the UK still remain deeply influenced by this post-war welfare state legislation (Glasby, 2012). In recent years however, attempts have been made to lead the care structure into new ways of service provision. Social care and social policy are broad terms covering a whole range of private and public activity. By definition, social care refers to a range of services provided by the state often in support of vulnerable people of all ages with physical and mental disability and illnesses. These services generally include adult care, personal care, home adaptations and social support. The National Framework for NHS Continuing Healthcare provides the following definition of social care in the UK: 'providing assistance with activities of daily living, maintaining independence, social interaction, enabling the individual to play a fuller part in society, protecting them in vulnerable situations, helping them to manage complex relationships and (in some circumstances) accessing a care home or other supported accommodation'.

2.2 Impact of Ethnicity on the User Journey

In this discussion, it's important to outline that the project focuses on the experience of people deemed as 'invisible minorities', whose facet of invisibility is presented as part of a description for the social markers of this user group. 'Invisible minorities' is a term coined in reference to people who are not always seen as part of a minority in the obvious way with which ethnicity is observable in the western world, i.e. skin colour. Social markers (the aspects of our identity that differentiate us), of invisible minorities, are often blurred or not at all present, which adds a certain degree of indistinctness. Too often, unrealistic assumptions that needs are met through this user group's own family and community are made by people and institutions put in place to support them (Schoenmakers, Lamkaddem, & Suurmond, 2017).

Some research has been conducted in the way different aspects of ethnicity impact access to health and care services. Even though research in the field of social care is scarce, an assumption can be made that similar barriers are present for immigrant elders in accessing state social care services. Discussed below, are three Scandinavian studies that depict a comparable difference in health and well-being as well as care service utilisation between native and non-native health and social care users (Verhagen, Ros, Steunenberg, & de Wit, 2014), (Verhagen, Ros, Steunenberg, Laan, & de Wit, 2014). The research shows a significant lack of health literacy and support in making sense of health and care support, all noted as just some of the qualities that foster disengagement with state health and social care services. Additionally, a lack of culturally sensitive care leads to the importance of specialised training and staff selection programs for improving cultural sensitivity. However, it is important to note that health and care workers are often required to initially possess strong ties within the local migrant community, in order for them to produce effective change and implement positive care and support methods (Verhagen, Ros, Steunenberg, & de Wit, 2013).

A study conducted on Black Ethnic Minority Elders (BME) in London by the King's Fund in 2002, showed that often, practical and logistical issues come into play and can seriously inhibit individuals, thus affecting well-being formats. The report referred to a lack of adequate care service advertising, poor service access, lack of interpretation services and lack of liaison with external independent sector service provider seriously harm BME care involvement (Kapasi, Silvera, & Consultants, 2002). Ultimately, a response and an appropriate action plan is required on behalf of the user from policy makers, service planners and practitioners, on influencing action, and developing ideas to facilitate change ("Experiencing ethnicity," 2004). Other research suggests we must place large importance on the feature of identity, specifically in co-design processes. Aspects of representation and identity formation, play a large role in understanding how to transform relations of power and encourage civic engagement (Renedo & Marston, 2011). In understanding the experience of immigration on a person's social and mental capacity, the diagram below depicts the different stages and impact.
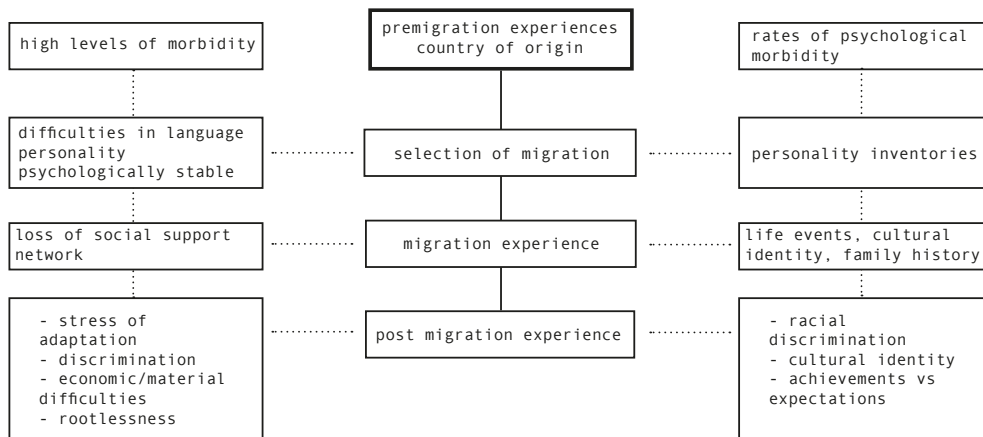
Figure 1. Stages of Migration and Psychopathology (adapted from (Ríos, 2008).

Psychopathology specifically references collective mental health features of a particular demographic, in this case, that of elderly immigrants and refugees as they experience similar psycho-social events in resettlement. The figure, with stages of immigration and the psychological impact each on personal experience and relationships shows a loss of social network from uprootal, stress of adaptation and rootlessness pointed out as being just some of the results of immigration. All people facing aspects of migration also experience the heightened need for cultural integration within their new environments. The older we are when resettling, the more amplified are risks related to cultural shock and anxiety from the experience. It has been described that these psycho-social intricacies place a large burden on the way people experience special services (Ekşi, 2002).

3   Case Studies

Purposeful case sampling was used for the selection of four countries in order to provide information-rich cases, studied in-depth (Patton, 2002). This sampling technique allows control over the search for specific cases to fit specific criteria (Bernard, 2000). The following countries were chosen to form part of this research due to their high GDP spend on health and social care, large proportion of elderly people and access to care. The purpose is to explore key features of well-established social care systems from economically developed countries. An important aspect to define was mandatory long-term care insurance, which meant that many of the country residents have free or subsidised access to state-run social care services. This criterion impacts access to state-run social care services for all citizens.

Country selection is based on following criteria:

Table 1 Case Study Criteria.

Country	Percentage of GDP Spent on Care for the Elderly	Percentage of People Aged 65+	Mandatory Long-term Care Insurance
Germany	10.1%	21%	1995
Denmark	10.9%	20	N/A
France	11.6%	20	2002
Belgium	10.7%	19	N/A
United Kingdom	9.4%	19	N/A

Source: World Bank, 2017 & The Organisation for Economic Co-operation & Development.

3.1   Germany

Following a major reform of Germany's care system in 1995, the country created a new model of service provision and funding, which allowed equal distribution of resources between central and local government, funded out of pay deductions. This offered universal and more appropriate care where and when it was needed, it helped relieve local councils from commissioning responsibilities by providing overall better quality care and releasing pressure from other parts of the system (Chazan, Lewis, & Neville, 2017). Over the next couple of decades, Germany saw a significant increase in demand on publicly funded care. By the end of 2011, almost 2.5 million people were dependent on state services ('The Local', 2014). Germany's social care is now effectively transferred and run by central government with overall GDP (gross domestic product) spend on overall social care of about 25.1% ('England's Social Care Crisis', 2018). The scheme is needs assessed and has been expanded to cover a variety of disabilities. It provides all residents with a reliable system of care, no matter what the circumstances. In addition to being 'inter-generationally equitable' (only workers pay to sustain it) it is also politically sustainable, with a growing reserve. However, since the model only covers basic needs, it has been argued that poorer people usually rely on other social benefits to meet their care necessities, whereas wealthier citizens account with their own savings. Thus, making the private care sector a distinct 'go-to' for some, expanding the field where generally, users cover the difference in cost. A key prediction for the German social care system is that over the course of the next few years, cost pressures may have a significant effect on operation. According to the Federal Statistical Office, Germany had a total of 767,841 non-German over-65s in 2013. Where most foreign seniors come from EU member states with Italy, Greece and Croatia ('How good is Germany for the elderly?', 2014). Over the past few years, funding for integration of migrants in the country has dramatically increased, with the bulk going to language courses (Konle-Seidl, 2017).

3.2   Denmark

Registered residents are usually automatically entitled to publicly financed care services. Operating on a regional basis, Denmark's social care provision is covered by its 'Health Law', which in turn assigns responsibility to regions and municipalities for delivering state services to vulnerable people (European Migration Network, n.d.). Principles include ensuring the delivery of high-quality care, access to information, service integration and transparency in activity. The national government sets the framework for elected councils to adhere to for specialised services and social care coordination. It has been noted that organised patient groups actually engage in policymaking at national, regional and municipal levels and are involved especially with care services. The country spends 2.2% of its GDP on care for the elderly, second only to Sweden, and Danes over the age of 65 receive a basic pension of about 8,000 krone (£811) a month, before tax. The rights of the elderly are championed by senior citizen councils in each municipality, and leaders from Denmark's five geographical regions meet with local authorities and practitioners to plan improvements to services every three years (Russell, 2016). The Danish model revolves around the idea of choice and prevention, with up to 24-hour home care available, free, for people aged 67 or older. Once people in Denmark hit 75, they receive two check-ups a year from a public health nurse to see if they need home care or other help. The nurse checks to make sure the fridge and medicine cabinet are stocked, whether the clients see friends and family, and whether they seem to be in sharp mental and physical health. Many people remain independent but sometimes people need help a lot earlier than they recognise - that's why there are

'supervised freedom' care homes available to them (Social and health care policy in Denmark).

3.3   France

The French social care system is partially funded by obligatory social security contributions, where premiums are automatically deducted from employee salaries (The Norwegian Health Care System, 1998). Three of the main central state services ensure the coordination and planning of social policy. A recently reformed concept introduced regional health agencies, which meant that several institutions were merged in order to manage the overall delivery of care services (Somme & de Stampa, 2011). These major regional and local state services for social affairs implement national policies and define and coordinate action at their levels ('France in London | A Comparison between the French and British Health systems', 2015). The key responsibility for elderly people with chronic conditions on the other hand, lay with two ministries and two insurance systems (ministry of health and ministry of solidarity, health and retirement pension insurance bodies). Additionally, social aspects of long-term care are managed mainly by the general councils at the department level following France's decentralisation policy (Somme & de Stampa, 2011). Care for the elderly (criteria for application is 60+ years old) is available via public monetary benefits and is means assessed using a national scale ('Alzheimer Europe - Policy in Practice', 2007). In regard to migrant users on the other hand, eligibility rests on two bases: lawful residence and occupational status. This is usually established by the provision of evidence regarding identity, residence and resources (Da Lomba, 2010). A large measure of access to care for North-African elders is granted via 'The Law of the Adaptation of the Society to Ageing' (Mandrin, 2017). This aspect of French policy permits a form of transition via a simple declaration, whereabouts North-African migrant elders are granted their French social rights whilst assisted long-term stay is provided within their home countries This provides access that many other ethnicities simply do not have. Another example of French government initiatives in support of elderly migrant comes in the form of semi-public organisation ADOMA, which includes improvement and adaptation of housing that meets the needs of this segment of the older population and providing healthy ageing personalised and targeted support (Mandrin, 2017).

3.4   Belgium

Providing a range of services, Belgium's long-term care system is financed by social security and general taxation contributions. Organised at the federal, regional and municipal levels, separate regions are generally responsible for economic migration and support in care. In 2012, 11% of the Belgian population held a foreign nationality and some research estimates found that around 19% of the population was foreign born. The main foreign nationalities in Belgium include Italian, French and Dutch. However, the most represented of the groups are those of Moroccan and Turkish descent, where ethnic elderly are among 1/3 of 65+, suffering from at least 2 serious chronic conditions. In order to help support this part of society, local authorities, municipalities and the Public Centres for Social Welfare provide cultural aid to minority people by covering the implementation of different integration initiatives set by government, such as housing and social assistance (Willemé, 2010). In recent years, the Walloon government initiated a program called 'The decree of 28 April 2016' which introduced compulsory integration schemes in local areas. The program included 120 hours of free French lessons for migrant communities among other new citizen orientation programs. With no major developments for social and healthcare access for

migrant citizens, access is currently the same as that of Belgian nationals (assuming residence has been granted) (Mussche et al., 2013). Overall, in spite of equal accessibility and integration programs, there are still groups of migrant communities who have less access to care, especially preventative care, as found by a study conducted to compare five EU countries (Rosano et al., 2017). Research concludes that aspects of 'diversity-oriented, migrant-sensitive prevention' are still highly required. Policies are also needed in order to mitigate barriers to care for immigrants, especially in areas where intersectional discrimination is still present. In order to reduce disparity, Belgium has been cited as one of the major European countries that fits regular public administration reforms into their model of authority. This empowers citizens and employees, increasing the quality of service provision; this model has been described as an 'overlap of their traditional administrative systems with more citizen orientation' (Torres, Pina, & Acerete, 2005). The key issues surrounding elderly immigrant care in Belgium, specifically labour migrants, as one report suggests are that of lower social and financial position, less knowledge of available care, all maintained by having little knowledge of the local language (Casal-Sanchez, 2018).

4   Expert Interviews

Hour-long, semi-structured exploratory interviews were conducted with specialists in co-design, service design and social identity. The purpose was to explore challenges within the public sector in co-design and service design, as well as to better understand ethnic and migrant experience with regard to public services. Grounded theory was used for the analysis method of the interview results, as the problem themes emerged out of the raw data. The following experts were queried:

Table 2 Expert Interviews Role & Field of Expertise.

Respondent	Role	Field of Practice
1	Freelance Service Designer, User Researcher & User Experience Designer	Local government, Service and Experience Design
2	Professor, Participatory Design Public Project Specialist	Community orientated participatory design, Local government
3	Professor of Social Policy, Social Citizenship & Migration	Social Exclusion-Inclusion, Migration & Social Policy
4	Researcher	Psychological & Behavioural Science, Social Identity & Representation
5	Co-design expert, ex-civil servant	Community projects, Refugees and Migrant experience
6	Professor, Service Designer	Service Design, Nomadic Experience

4.1   Service Administration: Disjointed associations

Experts agree that, as marketed private services become more readily available to the public, social care services fail to be more universal and often do not converge with the overall system of care. This severely impacts on the way elderly people use services as increasingly, not enough is being done to manage recovery when users become a part of a disjointed system of care. Policy on the other hand, gives a 'backdrop to hostility' with assumptions often made that immigrant elderly are being taken care of by their family members on an informal basis. This becomes a part of the generational stream & expectation, with what is

seen as the burden of care being moved elsewhere. A way to manage some of these challenges, experts agree, is to ensure thorough citizen-state involvement, where the user becomes expert by experience, allowing for family members who are also carers to participate in the research dialogue. Most importantly, within these processes, service users can be taught about the care service structure and availability. It is important also to note that specific discussion was formed along the themes of social identity and prejudice against marginalised groups of people within the system of care. It was suggested that a way to mitigate this issue is to ensure compassionate forms of training and care amongst service representatives on all levels of practice.

4.2   Service Design: Lack of user research and user testing

Respondents outline two major issues in service administration, design and delivery in the public sector. Most discussed is the lack of 'discovery phase', described on the UK Government website as a means of 'learning about your users and their context' (UK Gov, "Agile Delivery".), a process that helps to reduce uncertainty and assumptions made about consumer needs. Despite the UK Government Digital Service, which formed in 2010 to help improve and consolidate digital public services within central government, it seems much less has been done about the spread of the same user-centred values outside of central government. Another key issue discussed is a significant lack of user testing. Once projects near their service roll-out stage, designers would often administer technical testing to check for any interface instability without conducting in-depth usability checks. At this stage of the process, it is already too late to make any significant changes. Public services would often go through major transformations such as a channel shift from a physical to a digital representation, without acknowledging user requirements. Described as taking a passive view, institutions would assume the view of simply knowing what's best for the service user, and often unwittingly excluding elderly citizens and digitally illiterate service users.

When prompted about the cause of these major discrepancies, respondents listed issues of management, lack of resources and time restraints. In order to comply to these limitations, both designers and project management staff are said to 'cut corners' in order to roll out more projects in a shorter time-frame. One way to overcome these issues, experts agree, is to apply incentives that focus on quality and process management during the service design process. This motivates service designers and providers to adhere to the whole process of user testing and permit usability measurement. As suggested, a 'mandate discovery phase', could be the answer to fostering a better designer-citizen synergy.

4.3   Conditions for participation: The designer and wider community

Here experts speculate the changing role of the designer, especially within the co-design service session. The designer is referred to as sense-maker, one that establishes collective communication. They foster familiarisation by helping find a concept catalyst and common ground, in order to 'bring everyone to the same level', disintegrating feelings of fear often felt in dealing with the state. As part of the collective community building process, experts agree that it is up to the designer to build personal and collective awareness of cultural nuance and help the wider community adapt themselves, in order to create better conditions for participation. When often met with resistance, the only way to overcome it is through establishing community keyholders and establishing a panel reference group.

The final element of this process is expectation management. From the beginning of the co-design research process, it is important for the designer to clearly relay an understanding of

project outcomes and how findings will later be relayed to the wider community, actively closing the feedback loop. This important step establishes a reciprocal relationship.

5   Use, Emergence & Impact of Co-Design

The term co-design has long been used in both academia and practice, unconstrained by the borders of the design field. It is important to note that in the history of its development, the better known components of co-design emerged from aspects in the business and marketing fields, as opposed to design practice (Sanders & Stappers, 2008). Parallel to its growth in design, where it slowly began to emerge in 1970s Scandinavia, Michigan Business School Professors Prahalad and Ramaswamy popularised the concept of co-design as user involvement for 'co-creating value with the firm' (Prahalad & Ramaswamy, 2004). The key idea here, was to generate a sustained system of gain.

The value of co-design, could be argued, lays predominantly in its objective – 'not only involving users in service development, but also involving service developers in the realities their services are contributing to' (Holmlid, 2009). In other words, aside from the aspect of mitigating knowledge asymmetry from the perspective of the participant, co-design can tackle the issue of the all too known 'we simply know better'.

> *'To everyone according to their needs, from everyone according to their ability'*
>
> -   Karl Marx, 1875

Co-design is a democratic method, a mindset, a way to meaningfully engage "hard to reach" users, support change and build social capital, often requiring a diverse range of participants in exploring, developing and testing responses to shared challenges (Blomkamp, 2017). Co-design in healthcare innovation, for example, has strongly drawn on this premise of using design tools for improving varies aspects of the care quality service (Carr et al., 2009), here the concept of value changes form. Between 2005-2013, the former National Health Service Institute for Innovation and Improvement (NHS III), then in support of all NHS funded organisations, developed an experienced based co-design toolkit in order to involve non-design users into the service development process ("EBCD," n.d.). This was the beginning of tipping the scales of power in public service development, it emphasised the value of patient involvement and primary data collection to the overall process of service development.

5.1   Co-Design and the Dynamics of Power

Exploring use and opportunity and the Challenges of Co-Design: In discussing challenges surrounding implementation of the co-design process, we must address the proverbial elephant in the room. Issues surrounding citizen engagement and distribution of power within the process of service development are often discussed and could be addressed via Arnstein's 'Ladder of Participation' (1969). After her work in urban planning, Sheery Arnstein notes, there is a 'critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process' (Arnstein, 1969). Thus, it could be argued that fostering an environment where the shift of power is considered more of a fluid activity is key to truly engaging with a wider audience and optimising co-design processes. The figure below illustrates the notion of different sets of power held by participating citizens.
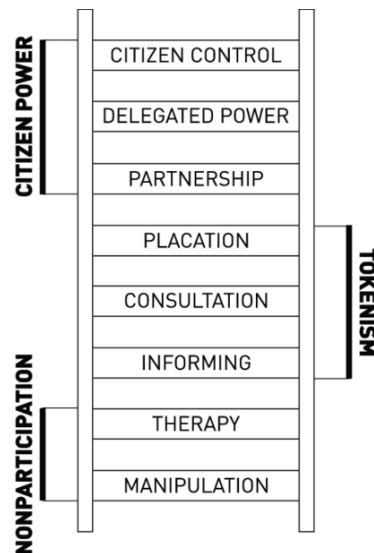
Figure 2. Arnstein's Ladder of Participation.

Types of participation and 'non-participation'

As rates of participant across different segments of society are found to be highly contrasting, especially amongst marginalised groups, it is important to illustrate that Arnstein's ladder of citizen participation specifically highlights some of the ways that empowerment takes place in any citizen-state partnership. The different rungs of the ladder represent different categories of 'power'. In order to nurture truly powerful community participation programs, we must first become aware of bias and power dynamics in order to prevent negative impact. The following descriptions take into account power processes within co-design:

Manipulation: This is the initial level at which all citizen-state relations begin. It is considered non-participative and achieves public support through simple public relations.

Therapy: This subsequent level aims to educate or 'cure' participants. It could be considered that in co-design for social care, participants become informed about public care structures and access to care. Very early stages of this process act as a form of engagement with the elderly immigrant user group.

Informing: This level is considered to foster a one-way flow of information during the process of co-design with the user group or stakeholders, no feedback is taken into account in order to improve processes for the future.

Consultation: This level begins to take into account power dynamics. Even by applying various ways of consulting the user group and stakeholders thorough public enquiry, this stage of the ladder is still considered a "window dressing ritual", as the final decision is usually still made by those consulting.

Placation: Stakeholders have more of an impact through opinions, ideas and outcomes. Here, two-way communication lays at the core. Hand-picked participants are requested into committees; however, final say remains with power holders in order to judge legitimacy of the feedback collected.

Partnership: At this level, power is redistributed amongst citizens and power holders. Planning and decision-making responsibilities are better shared amongst those involved in the process of co-design or project.

Delegated Power: Citizens have hold much more power on this level, this strictly ensures accountability and discussion on improving service appropriateness is strongly considered. Impact on this level is much more secure.

Citizen Control: This level does not account for intermediaries; all program and project processes are accounted for by the people.

6   Conclusion & Opportunity Identification

The current state of social care services in the UK shows a general necessity for improvement in the way services are run, disseminated and experienced by users. From this preliminary discussion we have found that too often user research isn't placed high on the agenda of UK municipalities. With strict time and funding constraints within authority often adding to the lack of sustainable models of governance and allowing assumptions to inhibit appropriate development. In light of this preliminary study, we can conclude that there is a need for more holistic commitment to the design research phase in UK government. Expert interviews reveal that the way to mitigate current issues of social care service design, administration and delivery, lay in effectively in administering mandate design and user testing processes. With a better understanding by all stakeholders of long-term value and impact of user research and co-design, we can ensure the development and improvement of state services for elderly immigrants. It is important to frame co-design as a useful approach for encouraging collaboration between practitioners and vulnerable or marginalised users, family members and staff, especially in complex environments. Therefore, the study lays out the potential for improved social care services, engagement and integration of elderly immigrants in the UK through principles of co-design. On one hand, working collaboratively with small communities of displaced elders will fundamentally help empower and instil active citizenship, allowing them to become a more integral part of the general population. On the other hand, it will improve efficiency in user research processes and arm service providers with knowledge of exactly what their users' requirements are.

The next stage of this research study will be to provide a better understanding of the UK social care service system. Further in-depth expert interviews are required in order to establish service design and delivery issues. Finally, co-design sessions with experts and elderly immigrants will help build guidelines for future development.

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