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# Identifying 'Extremes' in Complex Systems; Critical and Systemic Perspectives on the Concept of Extreme Users from a Study in Oral Health

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## Abstract

**The concept of 'extreme users' in inclusive and user-centred design serves as a valuable starting point for engaging with seldom-heard voices, uncovering latent user needs and fostering innovative design solutions. However, little attention is often paid to the biases and assumptions inherent in the identification and prioritisation of extreme users, and questions could be raised of the concept's value and relevance amidst the dynamic and expanding landscape of contemporary design research and practice. Within the domain of 4th order design (systems and policy), the conventional conceptualisation of extreme users, based on a single axis of product/service use, falls short in acknowledging complexities, intersecting dimensions and dynamic boundaries between extremes and mainstreams in complex systems. This article explores some critical and systemic perspectives on the concept of extreme users, drawing upon examples from research into inclusive oral health systems.**

## Keywords

***Extreme user; Healthcare; Health systems; Oral health; Critical; Systemic; Inclusive design.***

# 1. Context and Motivation

## 1.1 Reflections and Questions on the Concept of Extreme Users

Inclusive Design (ID) centres on designing with/for often ignored, marginalised or excluded populations. At the heart of ID lies the concept of 'extreme users'; offering designers a systematic means to recognize and engage with individuals and communities central to ID processes. These extreme users occupy the outer edges of the user spectrum; characterized by their unique abilities, specific needs, or unconventional usage patterns. By focusing on extreme users, ID aims to uncover insights that can inform the development of solutions benefiting both the margins and the mainstream.

Engaging with extreme users features in prominent human-centred design kits from IDEO (IDEO, n.d.) and Stanford d.school (Hasso Plattner Institute of Design at Stanford, n.d.), and ID processes often start with identifying an extreme user or scenario. However, often, little reflection is made on how we identify and prioritise these extremes - do our choices, consciously or not, reinforce certain biases and assumptions? Being driven by justice means not just designing inclusion for the underrepresented groups already highlighted or speaking out, but also for others who haven't yet raised their voices or have little or no power to do so.

Additionally, how can we identify and understand extreme users in a complex systems context? The application of ID and the consideration of extreme users in 4th order design (systems and policy) has been limited thus far, however, they are potentially relevant. In serving a complex system in flux, the mainstream inevitably shifts, leaving design solutions based on a previous

**mainstream inadequate. Instead, engagement with extremes grants a more critical, reflexive and holistic understanding of the system, enabling robust interventions and long-term system transitions. To identify and understand extreme users in this context, advanced perspectives are required which acknowledge complexities, intersecting dimensions, and dynamic boundaries between extremes and mainstreams.**

## 1.2 Application in Oral Health Systems

**This article explores the above questions, drawing from my doctoral research in oral health systems. Interestingly, the language of "extremes" is not unfamiliar in healthcare literature, as evident in discussions on "extreme consumers of healthcare" (Rafiq et al., 2019), and "extreme oral health" (Freeman et al., 2020). Moreover, from a design perspective, parallels could be drawn between the concept of extremes and mainstreams and attitudes towards, oral health and oral healthcare as outside of mainstream health and healthcare provision (Benzian et al., 2011) - despite evidence of the links between oral health and systemic health (Kane, 2017).**

**I suggest that ID, and the concept of extreme users, is highly relevant and potentially valuable to the pressing issues of oral health inequalities and equity, and current policy-driven transitions towards inclusive oral health systems (Leason et al., 2022). How those at the margins of oral health systems are framed and understood is significant, as it informs approaches to oral health inequalities. Current public health framings have been criticised as reductionist and deterministic (McMahon, 2023). Here, ID offers alternative and complementary approaches for understanding the extremes and mainstreams of the system, and uncovering valuable insights to inform transitions towards**

**inclusive oral health systems. My research in oral health explores these notions of 'extreme users' and 'extreme oral health' through a series of online surveys, interviews, public engagement and stakeholder workshops. The aim is to uncover definitions, dimensions and stories of mainstreams and extremes in oral health systems, and explore how these could be used to co-define an agenda for transitions towards "Oral Health for All" (Glick et al., 2021).**

## 2. Definitions and Representations of Extreme Users

## 2.1 Terminology

**As with much of design terminology, definitions and applications of the concept of extreme users vary. Table 1 presents an overview of terminology used in ID and similar fields relating to the concept of extreme users. Some definitions centre around disability, while others emphasise design interaction. Some simply equate extreme users with exclusion, whereas others distinguish two distinct types of extreme user i.e. power users and non-users/rejectors. The diversity in these definitions is influenced by the author's background and the specific context in which they are developed.**

| Term | Definition |
|---|---|
| **Extreme user** | **"Instead of the more typical mainstream design that aims to design for the average user or 80% majority, extreme user design aims to design for the other 20% or the users who are expected to be most affected by the design." (Hahn-Goldberg et al., 2022)**<br><br>**"People who do things in ways that average** |

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| | consumers tend not to think about." (Donovan, 2020)<br><br>"Determining who is an extreme user starts with considering what aspect of your design challenge you want to explore to an extreme. List a number of facets to explore within your design space. Then think of people who may be extreme in those facets." (Hasso Plattner Institute of Design at Stanford, n.d.) |
| Edge user | "Individuals and communities who are either excluded or struggle to access or use a product or service." (Report: Research Reveals Inclusive Design Can Expand Customer Reach Fourfold - Centre for Inclusive Design, n.d.) |
| Extra-ordinary user | "An individual person who happens to have a specific disability, as well as a range of other characteristics which are important for defining them as a person, but may not be related to their disabilities" (Pullin & Newell, 2007) |
| Critical user | "Users with severe disabilities (motion, sensory or cognitive impairments) who can illustrate the extreme end of the usability spectrum and on whom the impact of poor design is greatest in terms of function and stigma" (Dong et al., 2005) |
| Lead user | "People who make greater demands on a product, system, service or environment and therefore challenge it in ways beyond that of the average, mainstream user" (DOGA, n.d.)<br><br>"A lead user is an active and experienced individual |

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| | engaged in modifying and developing products for personal gain" (Pajo et al., 2015) |

*Table 1: Definitions relating to extreme users*

With terminology associated with similar populations being common both within design and other disciplines such as oral health, it is useful to distinguish the meaning and position of 'extreme users' in relation to these. Table 2 presents a spectrum of neighbouring terminology and definitions from design and health.

| Term | Definition |
|---|---|
| Vulnerable | "In need of special care, support, or protection because of age, disability, risk of abuse or neglect." (Office for Health Improvement & Disparities, 2022b) |
| Marginalised | "Individuals, groups or populations outside of 'mainstream society'." (Schiffer & Schatz, 2008) |
| Seldom heard | "Under-represented people who use or might potentially use health or social services and who are less likely to be heard by these service professionals and decision-makers." (Healthwatch, n.d.) |
| Under-served | "Those experiencing socioeconomic deprivation;<br>those with any of the protected characteristics described in the UK 2010 Equality Act; those not registered with a General Practitioner (GP); |

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| | homeless people; rough sleepers; asylum seekers; gypsy and traveller groups; sex workers; those in prison; those experiencing severe and enduring mental health problems, drug or alcohol harm issues or communication difficulties." (Office for Health Improvement & Disparities, 2022a) |
| Inclusion health groups | "People who are socially excluded, typically experience multiple overlapping risk factors for poor health (such as poverty, violence and complex trauma), experience stigma and discrimination, and are not consistently accounted for in electronic records (such as healthcare databases)." (Public Health England, 2021) |

*Table 2: Neighbouring terminology*

## 2.2 Visual Representations

Visualisations are frequently provided alongside definitions of extreme users, commonly using a bell curve, representing the user spectrum, with extreme users at the edges (Figure 1). This visualisation highlights two types of extreme at each end of the spectrum i.e. non-users/rejectors and power users.

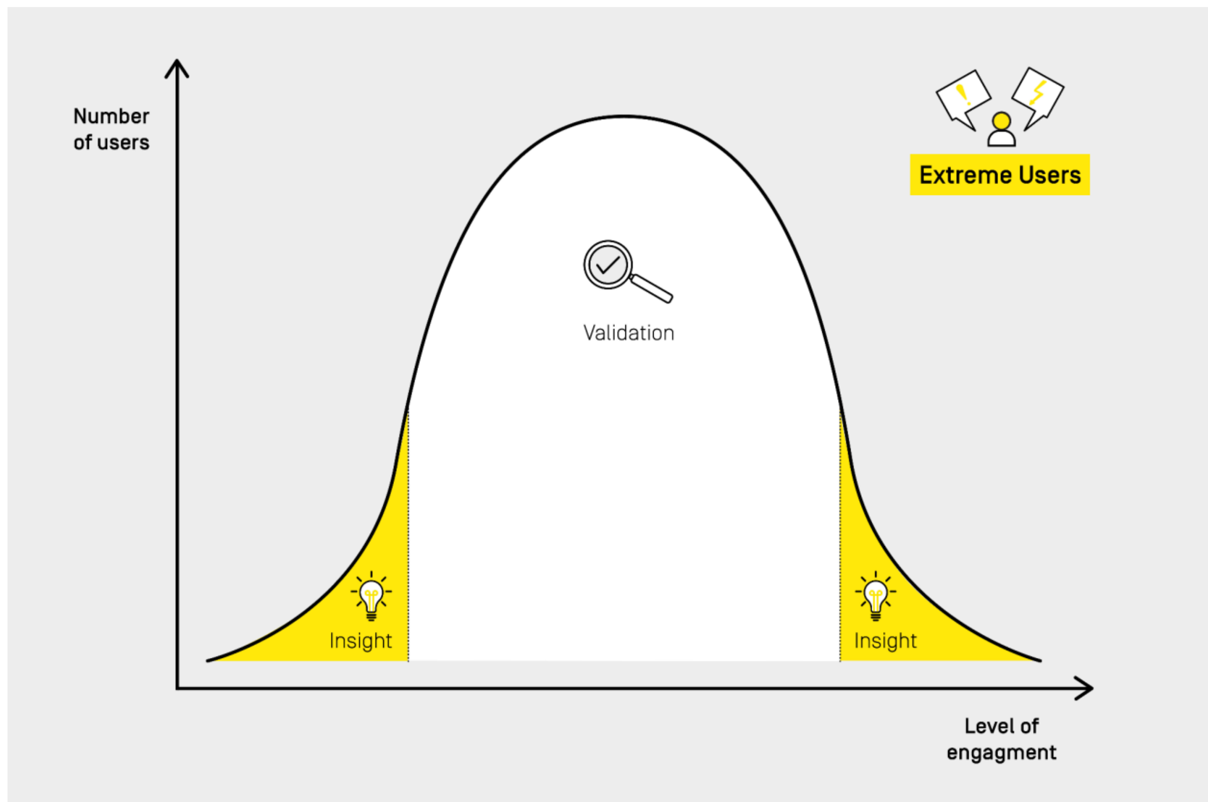


***Figure 1: Bell curve representation of extreme users (Meier, 2022)***

**The bell curve is a familiar visual for designers, however, such visualisations could be criticised as reductionist, simplifying the complex and diverse nature of people and multiple dimensions defining extremes and mainstreams. Moreover, one could question the very concept that there is a single 'normal' user, or a 'normal' distribution of users.**

**Treviranus (2018) offers an alternative visual of extreme users, using a 3-dimensional representation of a normal distribution - a starburst (Figure 2). This illustrates the complex and interconnected dimensions at play, but it doesn't so clearly visualise both ends of extremes i.e. the idea of power users.**

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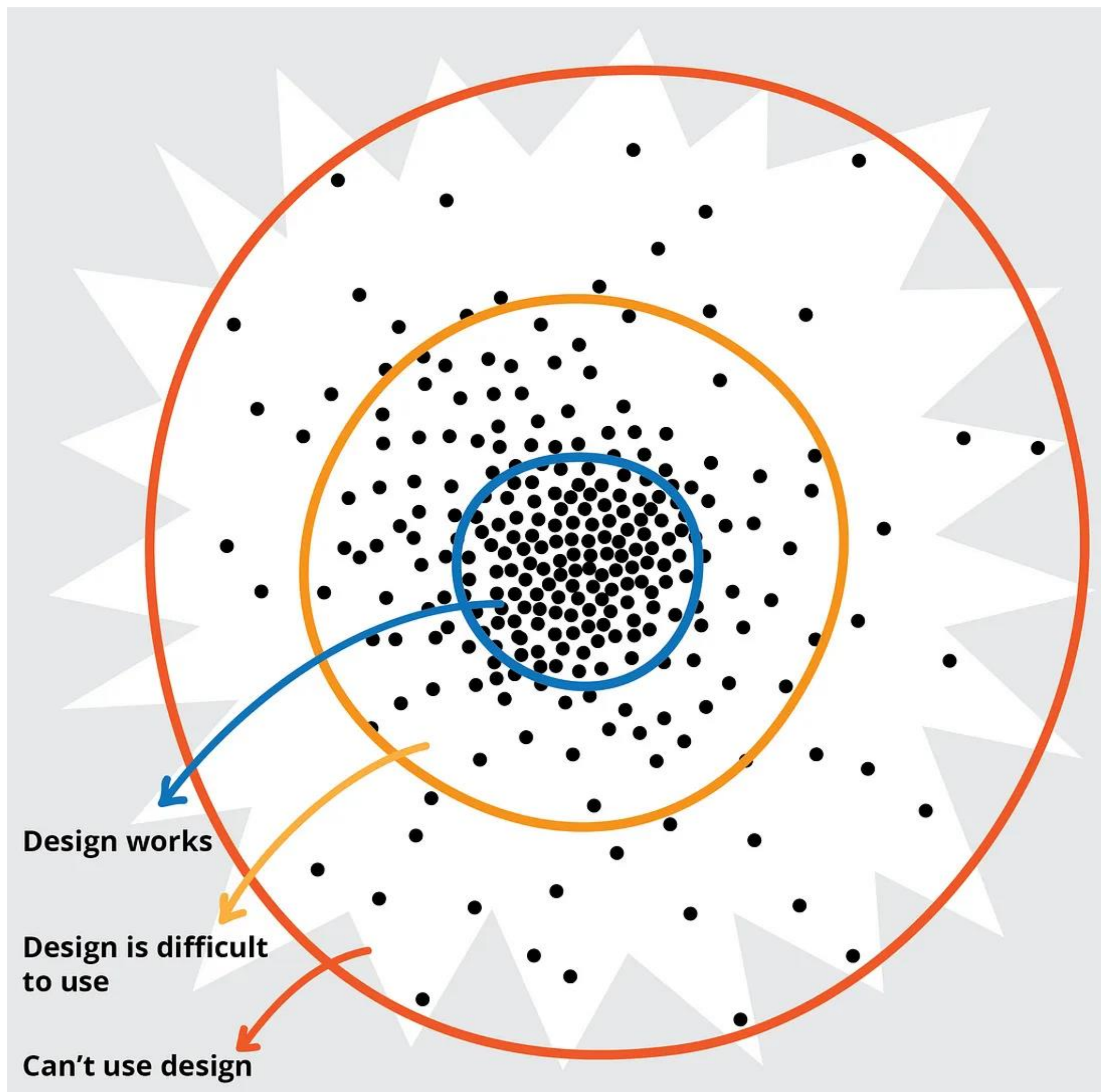


***Figure 2: Starburst representation of Extreme users (Treviranus, 2018)***

**Notably, while there are numerous visualisations and frameworks of determinants of health inequalities, no visualisations are commonly associated with any of the terminology in Table 2. This absence of visual representations may stem from the origin of extreme users within design, where visual communication is a prominent medium. Designers inherently gravitate towards visualising concepts for clarity and comprehension. However, the distinction also lies in the nature of the neighbouring terms, which predominantly describe specific population groups without contextualising them in relation to interaction with a product/**

**services/system. Unlike extreme users, these terms often lack a comparative dynamic with the mainstream, emphasizing vulnerability, marginalization, or underrepresentation without explicitly addressing their relationship with a normative reference point. This discrepancy highlights the unique positioning of extreme users as a concept.**

## 2.3 Distinctions and Positionality of the Extreme User Concept

**Following interrogation of these definitions and representations of extreme users and related concepts, I suggest three important distinctions of the extreme user concept:**

1. **Extremes are defined in relation to a mainstream. Identification and investigation of extremes requires a reference to something else. While this relational aspect is inherent in much of the neighbouring terminology (e.g. marginalised, socially excluded, seldom heard), none of these provide terminology for, or explicit recognition in definitions/representations of, a 'mainstream'. By explicit recognition of the mainstream, the extreme user concept lends itself to recognising the fuzzy boundaries and dynamics between the extremes and mainstreams.**
2. **Extremes users lie upon a spectrum(s) including both non users/rejectors and power users - both are useful to learn from. This is a distinction from a focus on excluded or marginalised populations, which recognises a spectrum and highlights power users.**
3. **Extreme is not an inherent individual trait or demographic group. It is a result of a mismatch with a product/service/system, that anyone could experience at any point (this could be for a short or a long time, and in one specific situation or multiple situations).**

## 3. Critical Perspectives on the Concept of Extreme Users

**This section presents some critical perspectives surrounding the concept of extreme users, supported by some examples and considerations from my research in oral health.**

### 3.1 Inherent Bias in Identification and Prioritisation of Extremes

***Description:***

**The process of identifying extreme users and deciding which to prioritise carries inherent biases, subject to observer-dependent contexts and judgments. It is easy to reinforce existing stereotypes or overlook certain groups, leading to skewed representations of extremes.**

***Example from oral health:***

**Oral health literature (dental public health, dental epidemiology, special care dentistry, inclusion oral health) and oral health professionals (practitioners, providers and policymakers) included in the research, identify extremes based on a range of factors such as: ability or motivation to access services, frequency of attendance (interaction with system), clinical need, oral health behaviours, oral health status, health status/medical history, lifestyle behaviours and social groups. Some of the different types of extremes identified by participants are shown in Figure 3. Often, the specific populations or individuals identified related to the professional experiences and contexts. It is important to capture all of these perspectives in order to get a more holistic picture of the extremes in oral health systems, as viewed from a diversity of system actors.**

**Some extremes within oral health may attract heightened attention and acknowledgment within research and policy, while others may inadvertently go unnoticed, slipping into the crevices**

**between service provisions and thereby perpetuating disparities in care. For instance, individuals with complex clinical needs might be recognised as extreme on one scale, yet find effective accommodation through specialist services. Conversely, those with less acute care needs, despite being less extreme on the clinical scale, might not receive adequate accommodation, illustrating a nuanced disparity in attention and provision.**

***Figure 4: Some of the types of extreme users identified in oral health***

## 3.2 Normative Assumptions

***Description:*** **The notion of 'extreme' conventionally implies a singular normative baseline, which may not adequately represent the diverse and evolving nature of reality.**

***Example from oral health:***

**In dentistry, the normative assumption may manifest when considering individuals who do not visit the dentist regularly. In certain contexts, these non-users might be categorised as extreme, deviating from the assumed norm of regular dental attendance. However, research participants have astutely pointed**

**out that non-users are, in fact, a common occurrence within the population. Moreover, the notion of an average utilisation of dental services is challenged, as there exists a broad spectrum of patterns and behaviours in accessing oral health care. This challenges the utility of categorizing extremes in oral health systems along a singular axis of use, recognizing that different norms may prevail in various contexts. The acknowledgement of context-specific normative baselines is crucial for a more nuanced and culturally sensitive understanding of what constitutes extremes and mainstreams in oral health systems.**

## 3.3 Language

### *Description:*

**The use of the term 'extreme' in the context of user categorisation can perpetuate othering language, which, consciously or not, may reinforce stereotypes and power dynamics.**

***Example from oral health:***

**Several public and professional participants expressed discomfort with the label "extreme," with one participant drawing a parallel to the term "extremist," highlighting the negative connotations associated with such language. This reaction underscores the potential for linguistic choices to carry unintended, stigmatising implications. Oral health professionals also commented on the language, emphasising the importance of adopting language that is widely recognised across the system, promoting inclusivity and avoiding the reinforcement of negative stereotypes. However, the value in diverging from individual trait-based categorisation and instead identifying individuals or groups based on specific situations, patterns of use, or behaviours was recognised as constructive.**

## 3.4 Dangers of Categorisation

### *Description:*

**Efforts at categorisation tend to compress the richness of individual experiences.**

***"When we categorize, we compress category members, treating them as more alike than they are; we amplify differences between members of different categories; we discriminate, favoring certain categories over others; and we fossilise, treating the categorical structure we've imposed as static."*** **(The Dangers of Categorical Thinking, n.d.)**

***Example from oral health:***

**Conventional dental public health approaches often identify and categorize entire population groups, such as those deemed 'vulnerable,' 'marginalised,' or 'disadvantaged.' This tendency to treat these groups uniformly overlooks the unique and varied needs of individuals within each category. In essence, by adopting a broad categorisation lens, the nuances and complexities of individual experiences and requirements are disregarded. Acknowledging, identifying and engaging with extremes in oral health systems necessitates a departure from such categorical approaches. The focus should shift towards acknowledging the diversity within these groups, ensuring that interventions and strategies are tailored to address the specific needs and circumstances of individuals rather than relying on broad categorisations that risk oversimplification and neglect of individual nuances.**

## 3.5 Complexity & Intersectionality

### *Description:*

**Extreme users, if defined based on a single dimension (e.g., disability or usage intensity), may oversimplify the complex**

**intersectionality of users' identities and experiences. Extreme users identities are interconnected and multifaceted. Overly simplifying these identities risks overlooking the nuanced intersections of characteristics, experiences, and needs.**

***Example from oral health:***

**Some oral health professionals involved in the research underscore the complexity and interdependence of the challenges faced by extreme users. Participants said that individuals often navigate *"overlapping and interdependent systems of discrimination or disadvantage".* The acknowledgement of multiple factors at play highlights the intricate web of circumstances that extreme users contend with, making their access to care a compound challenge. *"For extreme users the number of these factors increases and becomes insurmountable circumstances for accessing care".* This example links to the next section on systemic perspectives on the concept of extreme users, and emphasises the importance of embracing a holistic understanding of extreme users that goes beyond isolated dimensions and considers the myriad ways in which their identities intersect, shaping their unique needs and challenges.**

## 4. Systemic Perspectives on The Concept Extreme Users

**This section outlines some systemic perspectives, shedding light on the important broader contextual influences that shape the concept of extreme users and need to be considered within oral health systems.**

### 4.1 System as the Cause of Extremes

***Description:***

**System norms, regulations, and practices shape the criteria used to define extremes and mainstreams.**

***Example from oral health:***

**One oral health professional said, *"these [extremes] are set against systemic norms that make assumptions about service users"*. The boundaries moderating the extreme and mainstream are determined through policy and commissioning choices (e.g. mainstream and specialist services). Current oral health services and policies incentivise care for some while excluding others. It is also a system driven by the treatment of disease rather than prevention.**

## 4.2 Narratives Around Extremes

***Description:***

**Diverse narratives surrounding extreme users significantly influence how they are both defined and treated within various systems. The perspectives and stories crafted around extreme users shape the discourse, policies, and prioritisation strategies, ultimately impacting the allocation of resources and attention.**

***Example from oral health:***

**In the context of oral health, professionals' narratives play a pivotal role in shaping priorities and care strategies. When queried about future priorities, a notable sentiment emerged among some oral health professionals who questioned the need for prioritising extreme users. Some professionals expressed reservations, contending that extreme users are already adequately supported or that focusing on them would potentially delay the care provided to other users. These narratives reflect differing viewpoints on resource allocation and care distribution within the oral health system. While some argue for prioritising extreme users to address their unique needs and reduce significant demand on oral health systems, others caution against such prioritisation, emphasising the perceived availability of**

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existing support and expressing concerns about potential delays in catering to the broader population. The example highlights how narratives, be they supportive or cautionary, contribute to the shaping of policies and practices, influencing the trajectory of oral healthcare priorities and resource allocation. Understanding and unpacking these narratives is essential for developing a comprehensive and equitable approach to meeting the diverse needs of all users within the oral health system.

## 4.4 A Plurality of 'Mainstreams'

*Description:*

Systemic design isn’t bound to singular specific outcomes. It embraces plurality and aims to identify, develop and stimulate interventions to change and adapt the system in some way. In this context, the concept of a singular 'mainstream' is challenged. Embracing pluriversality acknowledges that there are multiple valid centres within a system.

*Example from oral health:*

Stakeholders emphasise that mainstreams can diverge significantly between and within specific service areas (e.g. specialist services) or contextual settings. This underscores the significance of where we choose to place the frame of reference or central focus. A recurring theme uncovered in our oral health research accentuates that, in the context of oral health services and systems, a non-user should not be perceived as a minority; their experiences and needs hold substantial relevance within the broader framework.

## 4.5 Language

*Description:*

The notion of labelling individuals as 'users' of systems prompts critical questions about the appropriateness of such terminology.

**This inquiry extends to the definition of extreme users – whether they are accurately characterised by the manner in which individuals use or interact with systems, or if their extremeness is a result of broader systemic determinants. The linguistic choice of terming individuals as 'extreme users' warrants careful consideration to ensure alignment with the nuanced realities of their experiences within complex systems.**

***Example from oral health:***

**labelling someone as an 'extreme user' may not fully encapsulate the complexities involved in their experience of oral health. Individuals enduring extreme oral health might be considered 'extreme' in an oral health system. This might not be because of their behaviour or experience as a user, but also by systemic barriers, economic disparities, and societal factors. In such cases, the term 'extreme users' may fall short in capturing the comprehensive landscape of influences contributing to their circumstances. This example underscores the need for a careful examination of language choices, advocating for terminologies that aptly reflect the intricate interplay between individuals and systemic determinants within the oral health domain.**

## 5. Identifying Extremes in Complex Systems

**The research into definitions and dimensions of extremes in oral health systems, described above, is ongoing. However, in this section I offer some initial sense-making relating to the identification of extremes in complex systems. Table 3 outlines some dimensions relevant to identifying extremes in complex systems; each with a translation in oral health. These should not be considered in isolation, or as single axes on which extremes sit, but as interrelated dimensions than can (in combination) help**

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**to identify extremes. The dimensions are separated into 3 interrelated levels:**

**(1) System Context:**
**The system context serves as the foundational layer, representing the external factors that shape the oral health system and establish the mainstream.**

**(2) Navigating the System:**
**This represents the pathways and interactions that individuals take within the oral health system. The nature of these interactions and scenarios can determine an extreme.**

**(3) Individual Perspectives and Experiences:**
**Individual perspectives and experiences are influenced by both the system context and the navigating layer. They include beliefs, experiences and characteristics that might lead to someone being extreme within a system.**

**An extreme user is someone whose interactions with the system deviate significantly from the norm or average, influenced by systemic factors, the pathways they navigate, and their individual experiences and perspectives.**

| Dimension | Translation in Oral Health |
|---|---|
| ***(1) System Context*** | |
| **Goal of the system.** | **The goal of an oral health system (at various international, national, local levels) might prioritise treatment, prevention, equity, holistic well-being, or patient-centred care - each bring nuanced perspectives on identifying** |

| | |
|---|---|
| | **extremes.** |
| **System-defined boundaries.** | **The way specialist/secondary dental care services are defined and commissioned defines who is treated in mainstream oral healthcare.** |
| **Political and policy landscape within which the system is located.** | **Influences such as funding cuts and lack of remuneration for prevention impact system dynamics between extremes and mainstreams.** |
| ***(2) Navigating the System*** | |
| **Desired/required journey through the system.** | **The oral health treatment pathway someone takes maybe common vs less common thus uncovering extreme/mainstream pathways.** |
| **Frequency of direct interaction with the system.** | **Regularity and consistency of engagement with oral health services, including routine dental check-ups and preventive visits.** |
| **Resources needed from system.** | **Both tangible (e.g., facilities, equipment) and intangible (e.g., time, information, support) resources required from the oral health system to meet individual oral health needs.** |
| ***(3) Individual Perspectives & Experiences*** | |
| **Social connections.** | **Connections with communities and their attitudes and behaviours towards oral** |

| | |
|---|---|
| | **health.** |
| **Beliefs about system.** | **Trust in providers, perceived efficacy of treatments, and cultural beliefs influencing oral health practices.** |
| **Previous experiences of the system.** | **Significantly positive or negative past interactions with oral health services or experiences of oral health problems/disease.** |
| **System literacy.** | **Ability to comprehend and apply oral health information, navigate the system, and make informed decisions about oral care.** |

***Table 3: Initial dimensions for identifying extremes in complex systems.***

## 6. Conclusion

**This article outlines critical and systemic perspectives on extreme users, drawing insights from a study focused on inclusive oral health systems. The critical perspectives presented reveal: inherent biases in identification and prioritisation, normative assumptions, linguistic challenges, dangers of categorical thinking, and the oversimplification of complexity and intersectionality. Systemic perspectives emphasise the role of the system itself in shaping extremes, the impact of different narratives, and the recognition of a plurality of 'mainstreams' within a system. The article concludes by proposing dimensions for identifying extremes in complex systems over 3 levels: system context (goal of the system, system-defined boundaries, political landscape), navigating the system (desired/required journey, resources needed, frequency of interaction) individual**

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**perspectives and experiences (beliefs about the system, previous experiences, system literacy, social connections).**

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