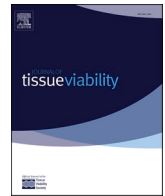


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Pressure ulcer prevention for people with long-term neurological conditions (LTNCs) who self-manage care and live at home

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ABSTRACT

Aim: To develop a Theory of Change (ToC) pathway to facilitate the development of a multi-component intervention package supporting pressure Ulcer (PU) risk identification and management, in partnership with people with Long Term Neurological Conditions (LTNC) who self-manage care and live at home, their informal carers and PAs.

Methods: A participatory approach, with extensive input from those whose lives are the focus of the research, was used throughout the 4 interlinked work packages (WP):

- WP1 – Development of two co-operative Inquiry Groups (CIGs)
- WP2 - Semi-structured interviews and/or app participation
- WP3– Professional and strategic stakeholder engagement
- WP4–Systems mapping and Theory of Change (ToC pathway development)

Iterative data analysis was undertaken with emerging findings from each WP informing subsequent stages of the study.

Findings: Overall, 74 participants contributed across the 4 WPs, incorporating 31 Service Users (SU), 8 carers, 9 Personal Assistants (PAs) and 26 professional stakeholders. We identified 8 key themes related to PU prevention, incorporating, learning, safe routines, third sector and peer support, navigating complex systems, adapting and reacting to change, perceptions of risk, risk negotiation and supporting roles. The findings indicate systemic and professional barriers which hamper people's ability to self-care and seek help.

Conclusions: The study highlights the complexities and impact of managing PU prevention activities at home for people with LTNC and areas of learning for health professionals and systems. By understanding these complexities we developed a systems map, identified resource requirements and illustrated a Theory of Change (ToC) pathway, to underpin future work to develop and user test an interactive, multi-component intervention.

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Abbreviations

Cerebral Palsy	CP	Personal Assistant	PA
Co-operative Inquiry Group	CIG	Pressure Ulcer	PU
Functional Neurological Disorder	FND	Service User	SU
Healthcare professional	HCP	Spina Bifida	SB
Long Term Neurological Conditions	LTNC	Spinal Cord Injury	SCI
Motor Neurone Disease	MND	Spinal Muscular Atrophy	SMA
Multiple Sclerosis	MS	Theory of Change	ToC
Muscular Dystrophy	MD	Work Package	WP
Myalgic Encephalomyelitis	ME		

1. Background

Improved life expectancy, changes to health/social care organisation, societal changes in attitudes to disability and personalised care funding, have led to increasing numbers of people with Long-term Neurological Conditions (LTNCs), living and working while managing complex health needs [1]. LTNCs include but are not limited to Multiple Sclerosis (MS), Spina Bifida (SB), Spinal Cord Injury (SCI) and Muscular Dystrophy (MD). They have a significant impact on individuals, families and carers, the NHS, and society. The estimated spend on people with LTNC is £3.5 % of NHS (£3.3 billion, 2012-13) and 14 % of social care budgets [1]. The need to transform services for those living with long term conditions was recognised in the NHS Long-term plan and associated strategic priorities [2,3]. A pillar of the plan is developing capacity and capability to support self-management and independence, particularly for those with complex needs.

People with LTNCs are often exposed to key pressure ulcer (PU) risk factors, including immobility, poor skin status and poor circulation [4]. Susceptible skin sites (e.g. buttocks and heels) can be exposed to pressure and lack of sensory perception may reduce the ability to feel/react to skin pain/discomfort and changes to soft tissues. Cumulatively this reduces tissue tolerance and increases the risk of PU development [5]. While limited data are available regarding PU prevalence in people with different LTNCs, a systematic review and meta-analysis of people with spinal cord injury estimated a high overall pooled prevalence of 32.36 % (95 % CI 28.21–36.51) [6], much higher than other general populations (7–14 % of hospital patients [7,8] and 0.51/1000 to 0.71/1000 of the community population [9,10]). Given that many people with LTNCs have mobility limitations and/or skin sensation changes, it is likely that their prevalence aligns closer to SCI populations, than general adult populations. A distinguishing factor of the LTNC population is the constant or fluctuation in PU risk they experience associated with their specific condition, overlain with gradual and acute escalation of risk. Some may also have cognitive difficulties impacting their ability to manage PU risk.

Where severe PUs develop, the often extensive timeframes involved in treatment have a detrimental effect on quality of life due to prolonged bedrest, coping with pain/smell/exudate, frequent home/clinic dressing visits, possible hospital admission for surgery/severe infection, work/education absence, and loss of employment [11,12]. Our Patient and Public Involvement group (Pressure Ulcer Research Service User Network (PURSUN)), who have a lived experience, highlighted the huge impact PUs have on both individuals and their families, with some describing PU development as ‘the last straw’. PUs also present significant financial burden to health care services [13–16] estimated at 4 % of the NHS budget [17] and a mean 1 year community patient cost of £1400 for Category 1 and >£8500 for Category 4 PUs [18].

People with LTNCs often self-manage their care needs independently at home, with or without support from informal carers (i.e. unpaid friends/family members) and/or Personal Assistants (PAs: care worker employed by an individual/family to provide support). Self-

management often occurs with little input from health (e.g. community nursing) or social (e.g. domiciliary care) services. The risk of PUs is often increased but overlooked during interactions with health services for chronic disease management and when they have an acute illness (such as chest infection) or ‘minor’ problem (such as minor surgery) due to the impact on their mobility or normal daily routines. Our research indicates that PUs may be severe before appropriate care is initiated with prevention opportunities missed [19].

While PU prevention has received a lot of attention from a clinical perspective, PURSUN identified the need to increase our understanding of how people with LTNCs who live at home, currently manage PU risk, and what resources are needed to facilitate prevention. The group emphasised the need to go beyond patient education models and consider if/how PU prevention fits within existing self-care regimes, lifestyles and services. This requires consideration from a broader systems perspective, to understand how health systems, contexts, and people react and interact with each other to identify challenges and possible solutions.

To address this research gap, we embarked on a programme of work funded by NIHR HS&DR (NIHR134029), entitled, Pressure Ulcer Prevention at Home: Pressure ulcer prevention for people with long-term neurological conditions (LTNCs) who self-manage care and live at home. A participatory intervention development approach.

2. Aims and Objectives

To develop a Theory of Change (ToC) pathway to facilitate the development of a multi-component intervention package supporting PU risk identification and management, in partnership with people with LTNC who self-manage care and live at home, their informal carers and personal assistants.

- To explore and understand how people living with LTNC currently identify and self-manage PU risk.
- To explore and understand the role of informal carers and PAs in supporting people with LTNC to manage PU risk.
- To map factors that help/hinder people’s ability to identify and manage PU risk (factors within the family, workplace, community and wider system).
- To explore the perspectives of healthcare professionals (HCP) and strategic partners on PU prevention at home, including the need for services to respond to informed, empowered service users (SU), facilitating self-care and blame/stigma avoidance.
- To identify and prioritise points in the system, which would most benefit from intervention.
- To develop a ToC pathway on which intervention development can be based.

3. Methods

A partnership approach based in the participatory research paradigm was used in this study. Participatory research seeks equal partnership between those conducting the research and those who the research is about, with stakeholders involved in every aspect of a study [20,21]. Within the context of this study, this means a collaboration between service users (SUs: people with LTNC who use NHS or social services), carers, personal assistants (PA: paid, non-clinical support worker/carer), Healthcare Professionals (HCP), third sector stakeholders (voluntary and community organisations, charities, or self-help groups) and academics. As is common within participatory research, many of those partners have moved between researcher and participant roles at different points in the study.

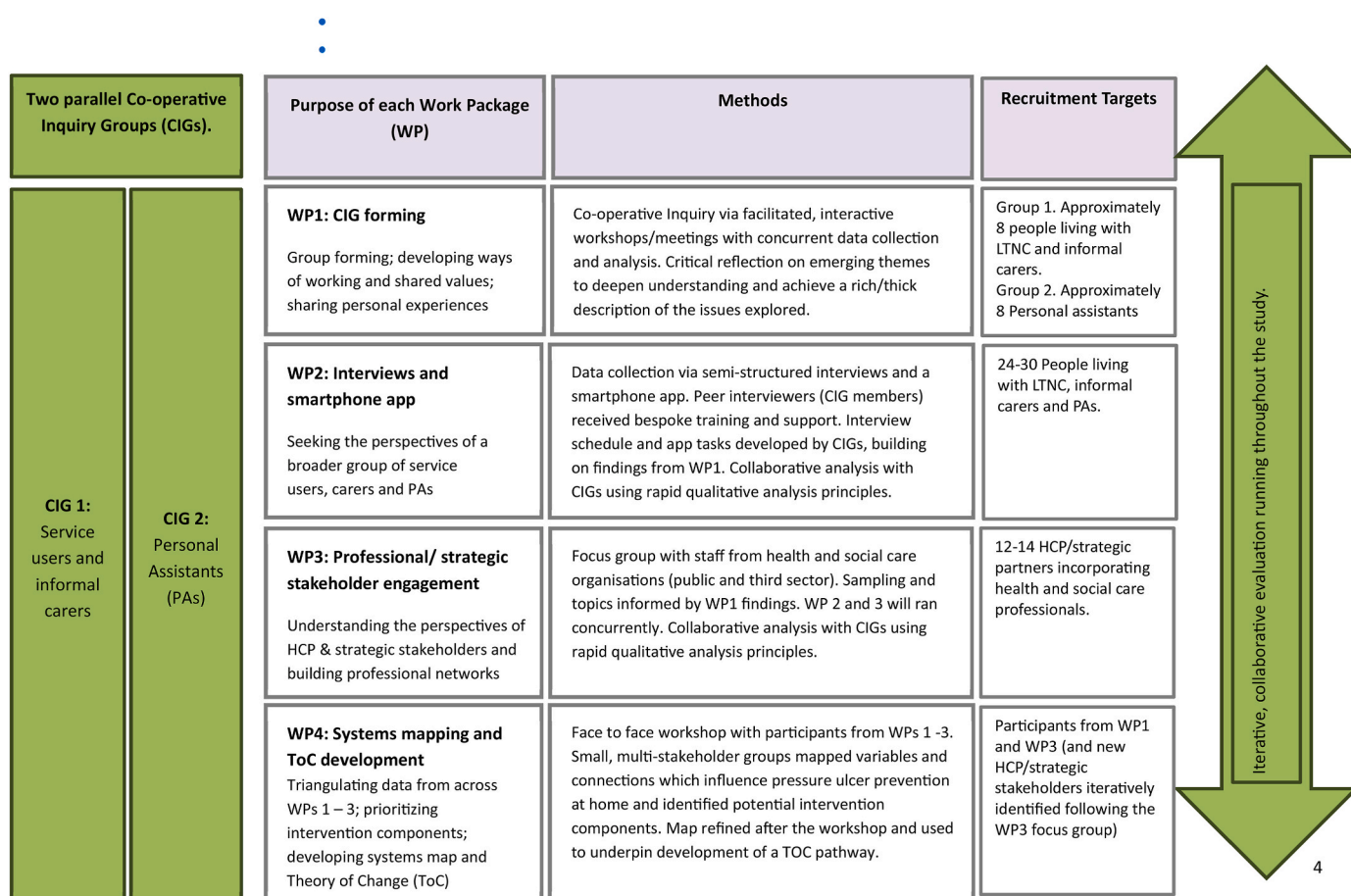


Fig. 1. Study overview.

The research comprised 4 interlinked Work Packages (WPs) described below and in Fig. 1 – Study Overview:

- WP1: Development of two co-operative Inquiry Groups (CIGs) (CIG1: individuals with LTNCs and their informal carers; CIG2: paid PAs) to underpin and support the design, management, data collection, analysis and conclusions of the work and explore their experience of identifying and self-managing PU risk (or supporting others to). Both CIGs also included University researchers [22].
- WP2: Seeking a broader perspective on PU prevention/risk with people with LTNCs, informal carers and PAs via semi-structured interviews (undertaken by CIG members) and a smartphone app [23, 24].
- WP3: Professional and strategic stakeholder engagement via a focus group [25,26] - to explore the PU prevention at home, including the need for services to respond to informed, empowered SUs as well those who are not, facilitating self-care and blame/stigma avoidance.
- WP4: Systems Mapping and Theory of Change (ToC) Pathway development - to co-create a visual representation of the systems associated with PU prevention from the perspective of key stakeholders, building on data collected in previous WPs, and a ToC pathway to underpin intervention development. Systems Mapping provides an illustration of key factors within a system and how they interconnect to create outcomes [27–30]. A ToC is a visual pathway, articulating how intervention components may impact intermediate, short and long-term outcomes and how contextual factors may influence change [31,32]. It is a flexible approach that helps to identify where the system may be resilient to change, informing intervention development.

3.1. Sampling and recruitment

Initially we had a period of broad outreach, through existing team contacts, third sector organisations, PURSUN, and snowballing, identifying potential participants and partner organisations for all WPs. We aimed to gain diversity of experiences in terms of LTNCs, previous PU experience, role (i.e. service users, carer, PA, HCP), age, gender and ethnicity. Sampling was undertaken iteratively with emerging findings identifying gaps in stakeholders and findings, which informed sampling for subsequent work packages. More detailed sampling information can be found in the study protocol [33], synopsis [34] and Fig. 1.

3.2. Ethical considerations

The study included discussion of potentially emotive health topics (e.g. during CIG meetings and interviews) as participants were asked to draw on their experience of living with long term conditions. It also involved challenging discussions across professional and professional-SU boundaries, for example exploring issues within healthcare services with different HCPs, SU’s and carers during a systems mapping workshop. University staff with experience of facilitating the involvement of participants with lived experience, were available to provide support and signpost to appropriate clinical/support services, if needed. There are published ethical considerations associated with participatory research, which guided our ethical principles and practice [35].

Ethical approval was sought and approved through the University of Leeds Medicine and Health Research Ethics Committee. Prior to recruitment a detailed study information sheet was provided to all participants and informed consent was sought by the University researcher.

3.3. Data collection

Co-operative inquiry groups are groups of people with personal experience of a topic who meet regularly to plan, investigate, and reflect on the topic. Supported by university researchers and underpinned by an adapted version of Heron's co-operative inquiry methodology [22], the CIGs undertook the following.

- Group forming – Creating a safe space and developing a written partnership agreement and shared values.
- Self and group reflection – sharing personal experiences of managing PU risk, LTNCs and identifying common themes.
- Preparation and training for WP2 –co-designing interview topic guides and app tasks. Volunteers from each CIG also agreed to undertake peer to peer interviews and user-test and monitor the app. Tailored interview preparation, training and support was provided.
- Continued immersion - the CIGs met regularly throughout the study, moving between participant and researcher roles at different points in the research.

SUs, carers and PAs in WP2 participated via a semi-structured interview, a smartphone app, or both. Interviews were conducted by CIG members (SU, carers, or University researchers), either face-to-face or online via a video call. Interviews took approximately 1 h. App participants were sent tasks over a 2 – 3-week period via Fieldnotes (<https://www.fieldnotescommunities.com/>), a smartphone app. Tasks invited people to share their day-to-day experiences of self-care or supporting others [36]. The WP3 face-to-face focus group with HCP/strategic partners was facilitated by university researchers around a topic guide informed by the CIGs and WP1 findings [25].

In WP4, we held a face to face, full day workshop. Emerging study findings were presented as a composite case study, developed by CIG members, and presented by an actor. This brought the data to life, whilst maintaining the anonymity of participants. In 3 small, facilitated, mixed stakeholder groups participants reviewed the draft map and identified points that would benefit from intervention. After the workshop, university researchers refined the map and ToC combining comments from across the small groups. This was followed by multiple rounds of review and feedback with workshop participants and wider CIG members.

3.4. Analysis

Qualitative data from all WPs were recorded and managed in NVivo. Analysis was informed by the principles of rapid qualitative research [37] and collaborative framework analysis [38,39]. During WP1, CIG members identified and recorded common themes emerging from their discussions which were used to create a Rapid Assessment Procedure (RAP) sheet and the NVivo codes. This enabled summaries and emerging findings to be shared iteratively, throughout the research process. RAP sheets were completed after data collection activities (interviews, app tasks, relevant CIG meetings and stakeholder focus group) and discussed as part of collaborative data analysis workshops with both CIGs. Participatory techniques were used to facilitate collaborative accessible data analysis within the CIGs [34].

4. Project management

A Programme Co-ordinating Group (PCG) met bi-monthly over the course of the 2-year study. The group combined: clinical academic; specialist nurse; specialist neurological physiotherapist; social care; and qualitative and participatory methods expertise; with personal experience of living with a PU/PU risk, patient advocacy and caring for someone with a LTNC. The PCG used their extensive expertise to support and guide the CIGs and provide oversight of the whole programme of work. In addition, a Programme Steering Committee with 6 independent members from the social care/NHS sectors and a member with lived

experience, oversaw research conduct and progress, meeting bi-annually.

5. Results

Across the 4 WPs, 74 participants contributed incorporating 31 service users, 8 carers, 9 PAs and 26 HCP or strategic partners. Participants with a lived experience of LTNCs, included (but was not limited to) those with MS, SCI, SB and MD. Participants had varying health and life experiences making it challenging to describe our population in a transparent manner, while recognising the multifaceted and fluid nature of people's identities. For example, some HCP and people with LTNC also had a caring role within their families, and some informal carers described the impact of their own health conditions. Appendix 1 provides a comprehensive overview of SU, carer and PA characteristics and demographics and how they participated in the study. HCP and strategic partners included (but was not limited to) Specialist Nurses, OTs, Physiotherapists and general practice as well as those from third sector organisations. Appendix 2 details a comprehensive overview of professional and strategic stakeholder characteristics and their contributions to the study.

We identified 8 themes across all WPs including, learning, safe routines, third sector and peer support, navigating complex systems, adapting and reacting to change, perceptions of risk, risk negotiation, and supporting roles. Each theme is illustrated in the systems map demonstrating the complex nature of PU prevention and possible interventions to improve the current situation (Fig. 2). An explanatory narrative summary of the themes is also detailed below.

5.1. Learning

Participants shared varying experiences of PU prevention learning and support. Some reported never receiving (or not remembering) any information about PU prevention or that they only became aware of their PU risk through involvement in this study. Those participants emphasised the need for PU awareness raising activities. Others were very aware of their risk and had already integrated PU prevention into their lives. They were more concerned about when and how to seek help for PU development/deterioration.

People who had received PU prevention support reflected on the timing and delivery of that information. Many people with spinal injuries mentioned a focus on skin care during their early rehabilitation. However, people talked about the context of their situation (i.e. life changing injury) making it difficult to take in information or engage with future risks.

‘The problem is that there is SO much information to take on board when you are newly injured, you don't know what is life-threatening and not. There's so much information it's a little overwhelming’. (service user)

Factors such as fatigue, mental and physical health, literacy, stress, and cognitive impairments were also acknowledged as impacting people's ability to seek out, process and act on PU prevention information. Participants noted that many existing resources (e.g. leaflets) focussed on understanding clinical risk factors and lacked consideration of wider contextual issues and how to adapt PU prevention strategies within their busy and changing daily lives. The importance of health information being staggered or repeated over time and HCPs tailoring information to the individual were also noted. There was a feeling that some HCPs saw the provision of PU information as a ‘box ticking exercise’ rather than part of true shared care and decision making. At times, people reported inconsistent PU advice from the different HCPs.

Participants also shared some positive examples of PU prevention education particularly with Tissue Viability services and Spinal Injuries Units (SIUs). However, it was noted that Tissue Viability Nurses (TVNs) were rarely involved in prevention, with some participants suggesting

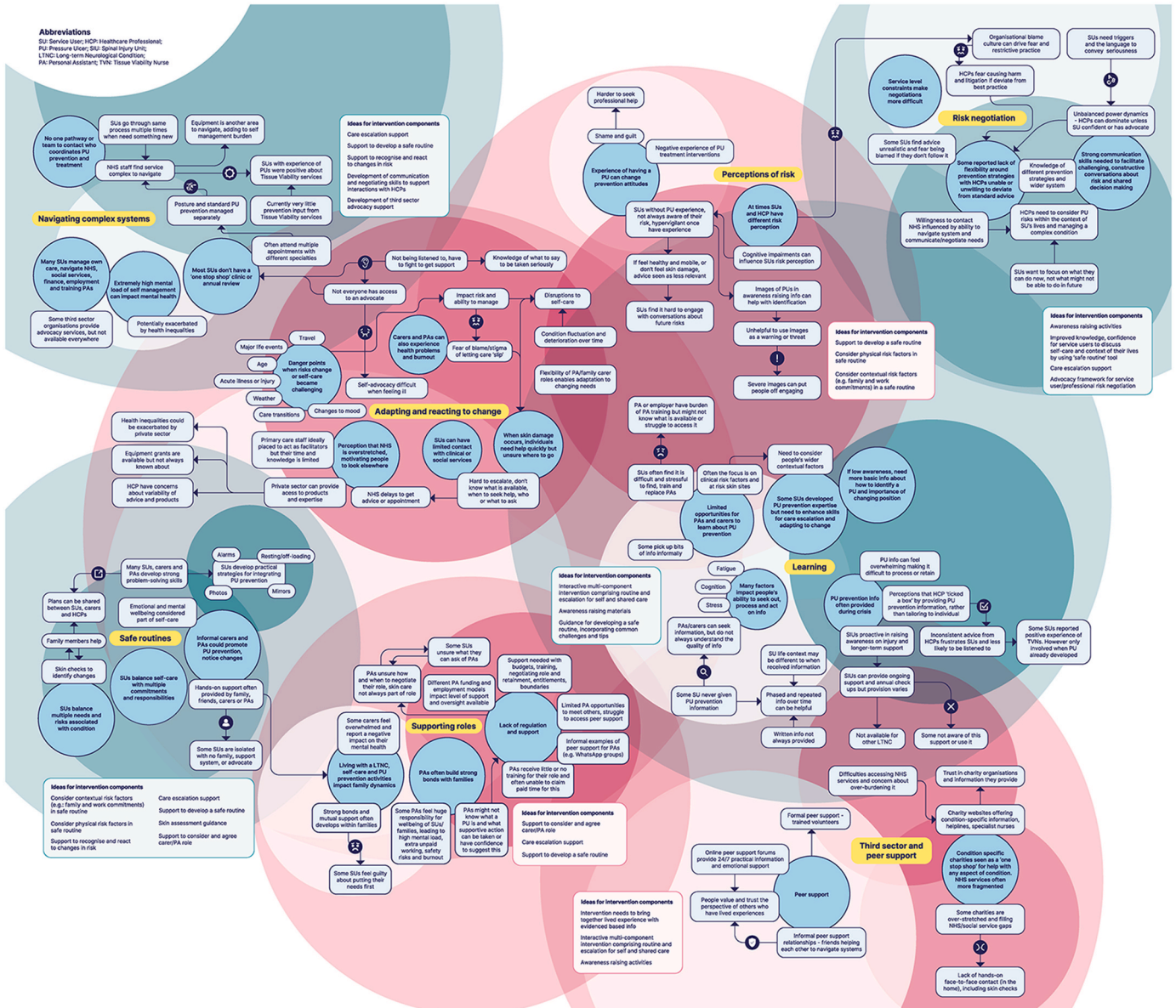


Fig. 2. Systems map overview and clusters.

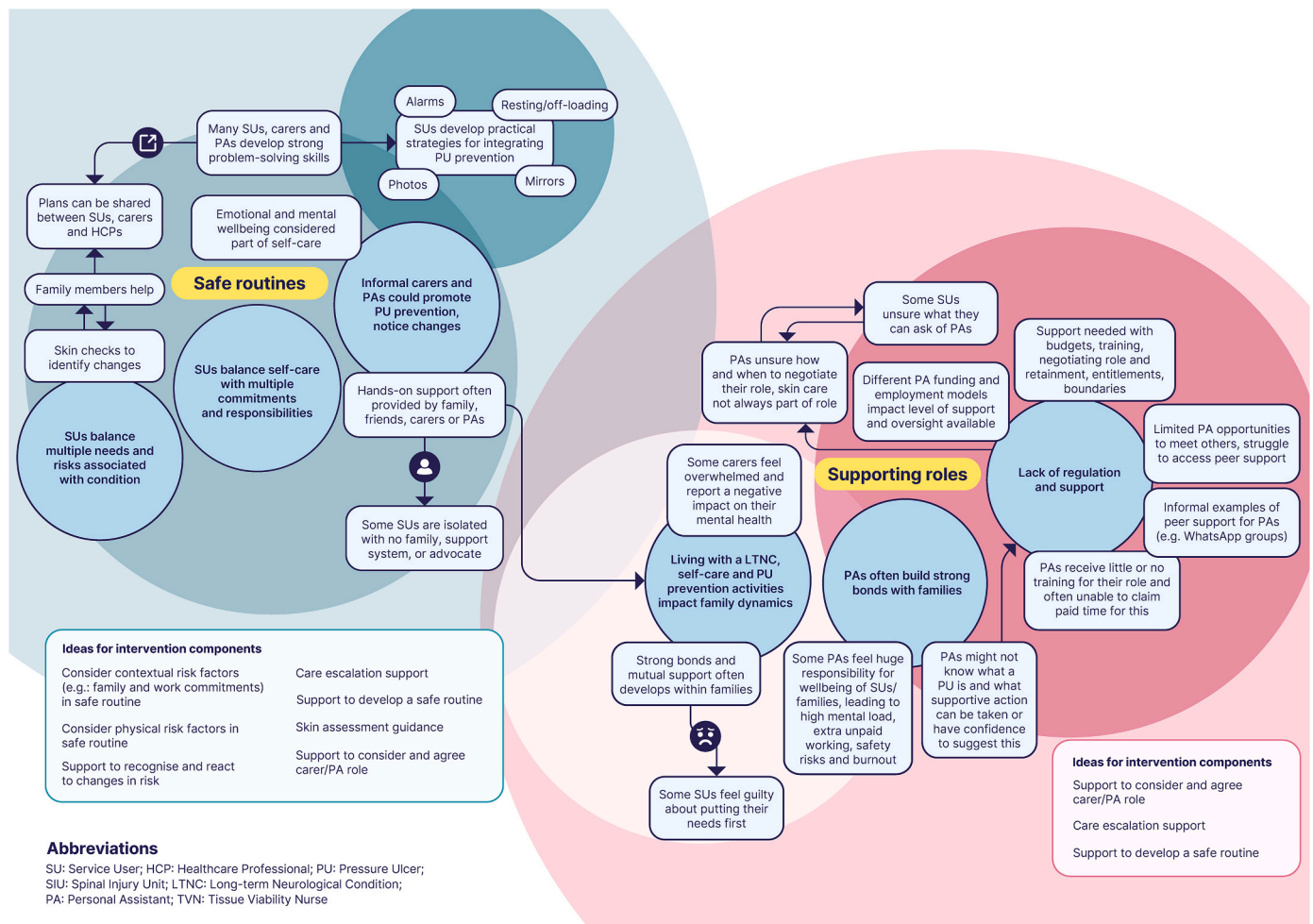


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there was opportunity for a more active role. It was also recognised that SIU service provision varies and is not replicated across other LTNCs.

5.2. Safe routines

For many SUs, PU prevention was a small part of a more complicated self-management context, with people highlighting the importance of mental health and emotional wellbeing alongside physical care. Many participants described developing problem-solving skills to support their self-care or the care of others. For example, despite a recognised gap in appropriate prevention resources, many people developed successful routines and shared strategies (e.g. using mirrors/photographs to monitor skin, setting alarms to prompt repositioning, specialist clothing, getting help from others) which helped them to live PU free.

“I’ve got more photos on my phone of [husband’s name’s] bottom! I’ll take a picture and I show it because that’s the only way he can see it really. He’ll try it with a mirror but it’s easier. I’ve got a record on the phone then, you have to show him what it looks like because he can’t feel anything ...” (Informal Carer)

Some WP4 participants conceptualised this kind of activity as a ‘safe routine’ i.e. a set of flexible prevention activities developed around the specific needs of an individual, taking into consideration their clinical risk factors and wider issues impacting their daily lives.

5.3. Third sector and peer support

We found that third sector organisations were highly valued in the support of people with LTNCs, their carers and PAs. People talked about accessing trusted charity websites, charity funded specialist nurses, newsletters, helplines and training. Multiple forms of peer support were also described, including trained peer support workers, social media forums, and informal peer support from friends. People cited several reasons for seeking support outside of the NHS, relating to gaps and complexities of accessing correct services within the NHS; long waits; minimising the burden on overstretched services; and valuing and trusting the perspective of others who have lived through similar experiences:

“Disabled people respond to other disabled people” (Service User)

However, some people were mindful that advice given by peers was often based on just one person’s experience and therefore may not be accurate or appropriate for other people’s circumstances. Some identified a gap in resources which bring together evidence-based information and peer experiences.

5.4. Navigating complex systems

SUs noted the complexities of managing their care, requiring negotiation of multiple, complex systems and processes, including NHS and social care services; finance (e.g. benefits, equipment); recruitment; employment and training of PAs; and third and private sector input. In

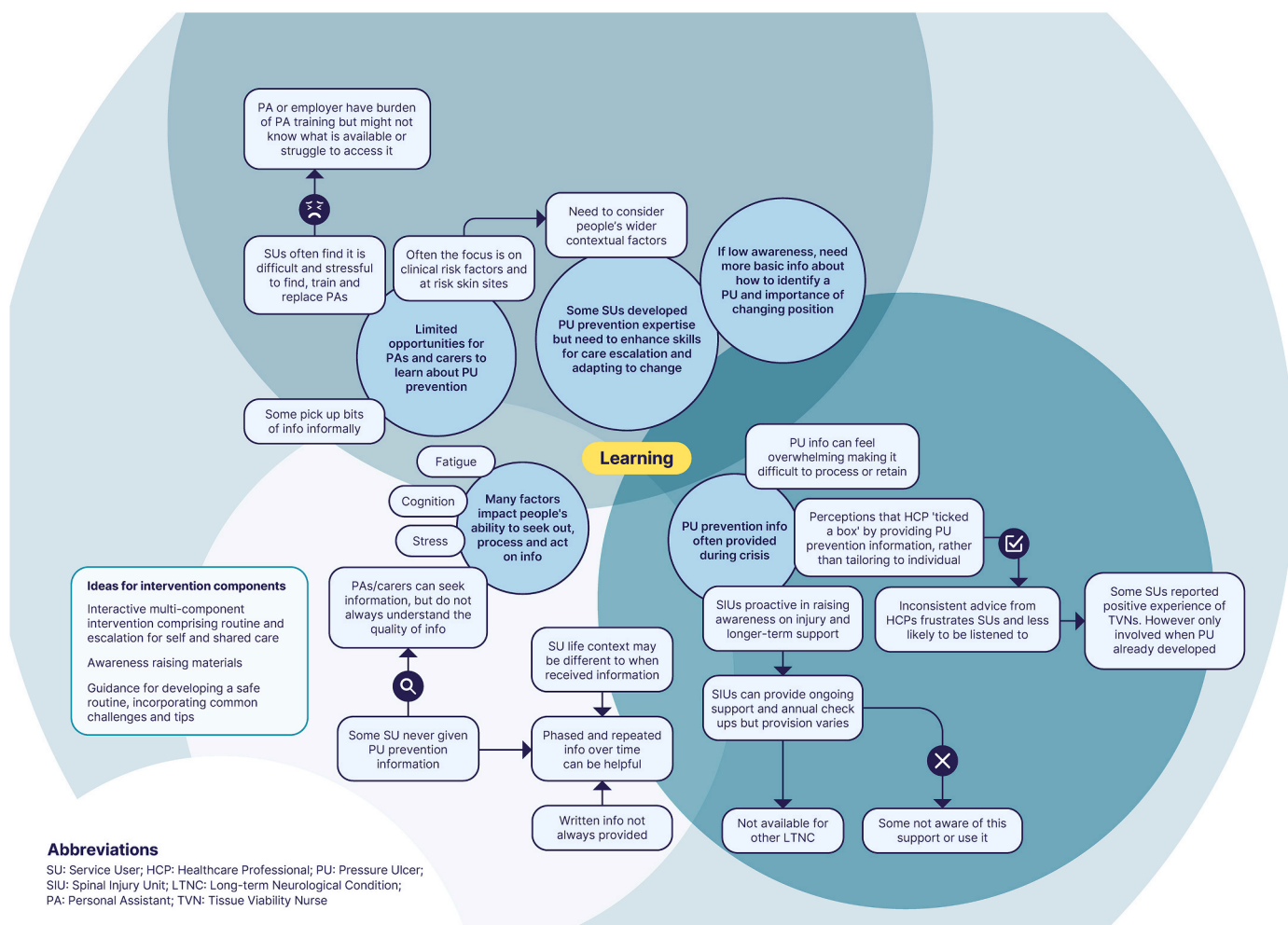


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addition, many people with LTNCs are required to attend multiple appointments with different specialties, as they do not have dedicated clinics or annual reviews. This is further complicated by PUs being a cross specialty condition with variable patient pathways. These complexities make PU care escalation difficult. Many reported delays in getting support via primary care and many did not know where else to go.

“They told you the signs to look out for but what I found was when I came home and I got a pressure ulcer, I didn’t actually know what to do. Everyone was very clear that you don’t want one, but no one could actually tell you what to do when you did get one”. (Service User)

Many of the frustrations felt by service users, carers and PAs were shared by the HCPs in this study. Some HCPs reflected on their own experiences of being family carers and still experiencing challenges in getting appropriate, timely support, despite their enhanced knowledge.

“It’s because the way that systems work is that we’re all in silos, aren’t we? We’re all in different departments, we’re all funded in different areas, and you’re told that your remit is to do this, and we’re not funded to do anything outside of this, so you then go and do your job, and even if you raise it and say, “This needs looking at,” if you don’t know who to go to, what do you do with it?..

(HCP stakeholder)

Some SUs, carers and PAs described slowly increasing knowledge of their local systems and what to say to be taken seriously, but others did not feel listened to by HCPs or were blamed for PU development, causing them to disengage. People described tensions between SUs and HCPs regarding the most suitable equipment or where HCPs were unable to provide specific products due to local policy. Some people were unaware of equipment grants being available via the third sector and others described them yet another bureaucratic process to navigate. Many SUs valued the expertise of the private sector, seeking their advice when they did not feel supported by the NHS. However, some professional participants raised concerns about the evidence base of some products and the variability of advice given.

Many people talked about the stress associated with self-management, with some reporting it impacted their mental health, and people reflected on the challenges of self-advocacy, particularly when feeling unwell, fatigued, or low. We found that people’s previous experiences of the NHS had an impact on their ability and willingness to self-advocate.

5.5. Adapting and reacting to change

SUs described ‘danger points’ in their lives when their risks changed or where self-care became more challenging or less of a priority. They were sometimes unsure of what to do when their prevention strategies no longer worked or were no longer practical. This was often linked to

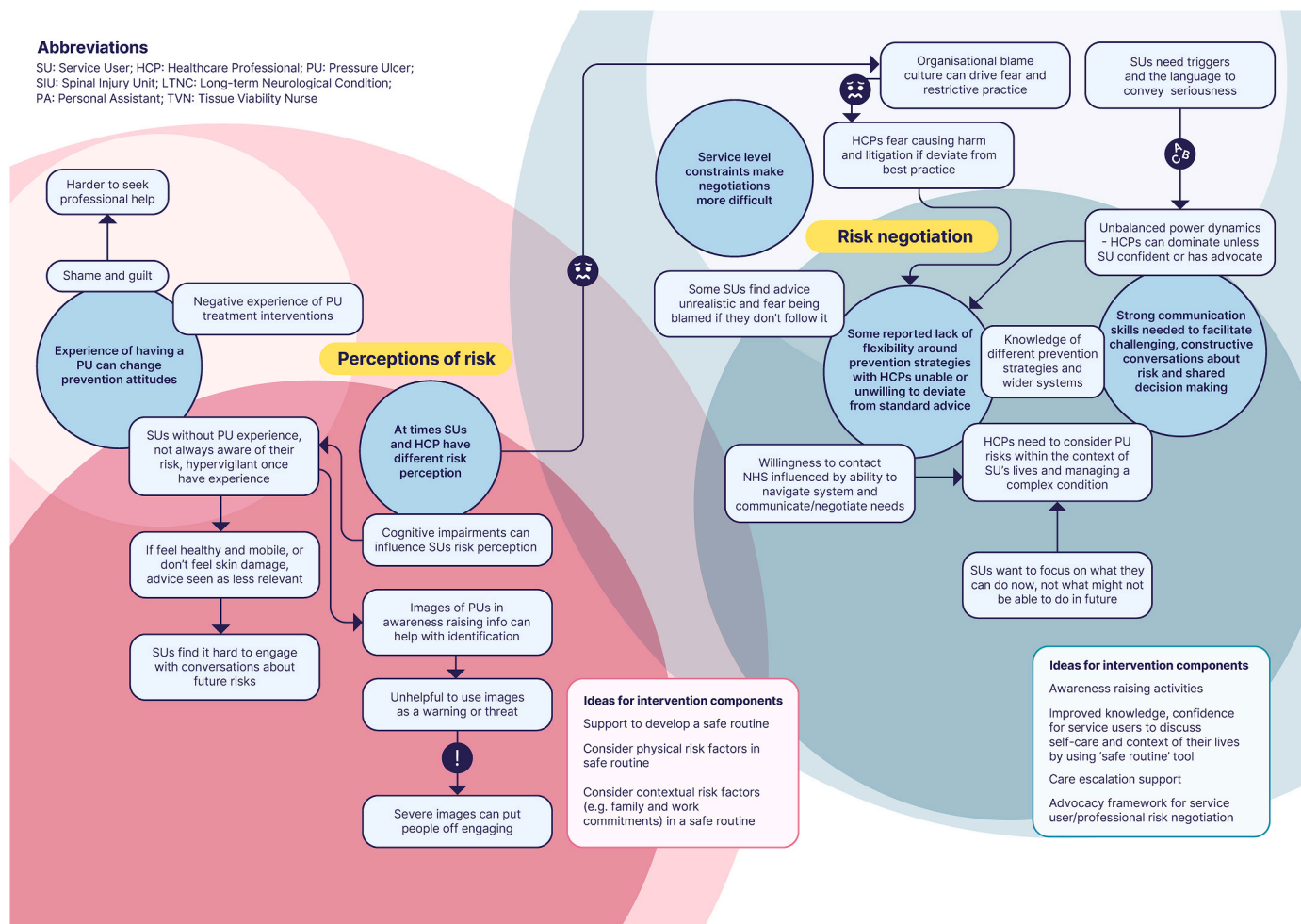


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wider contextual factors impacting their life such as specific events (e.g. bereavement), temporary changes (e.g. holiday), care transitions (e.g. change of support), illness/injury, changes in mood (e.g. depressed, unmotivated), aging and deterioration or fluctuation of existing LTNC or developing new conditions. HCP participants reported feeling frustrated by the lack of flexibility within their roles to support this.

5.6. Perceptions of risk

We found that that people's perception of their PU risk changed over time. For many, 'risk' was quite an abstract concept and some people found it hard to engage in conversations about future risks. Some SUs said they had not appreciated the importance of PU prevention, and the potential seriousness of PUs, until they had experienced a problem. They reported becoming 'hypervigilant' after experiencing a PU, in part due to the significant impact of treatment interventions (e.g. bedrest, inability to attend work, education, and be involved in family life) and the subsequent emotional and mental health impact this had on individuals and families. Some HCP participants also suggested that cognitive impairments may affect how SUs perceive and make decisions about risk.

"I lost 6 months of my life" (Service User)

5.7. Risk negotiation

Our findings indicate tensions between the level of risk that SUs are prepared to tolerate when compared with the HCPs who support them. SUs described considering PU risk within the wider context of their lives. HCPs risk tolerance appears to be influenced by their level of experience and constraints in their role or organisation. For example, time limited and task-oriented appointments, being unsure what else they could offer, a culture of blame, and fear of litigation if deviating from best practice. People also had different perceptions/understanding of the potential seriousness of PUs. These differences impact people's ability and willingness to negotiate risk and come together for effective joint decision making and can result in unsatisfactory prevention activity for all parties. This sometimes leads to SUs being labelled as 'non-compliant' or even blamed if a PU developed or deteriorated, causing some people with LTNCs to disengage with clinical services.

"23 years ago I discharged myself from the neurological care due to frustrations about the continual repetitive visits that did little to support me with getting on with my "normal life"... I found the system was geared at telling me what not to do and not supporting me with the things I wanted to do" (Service User)

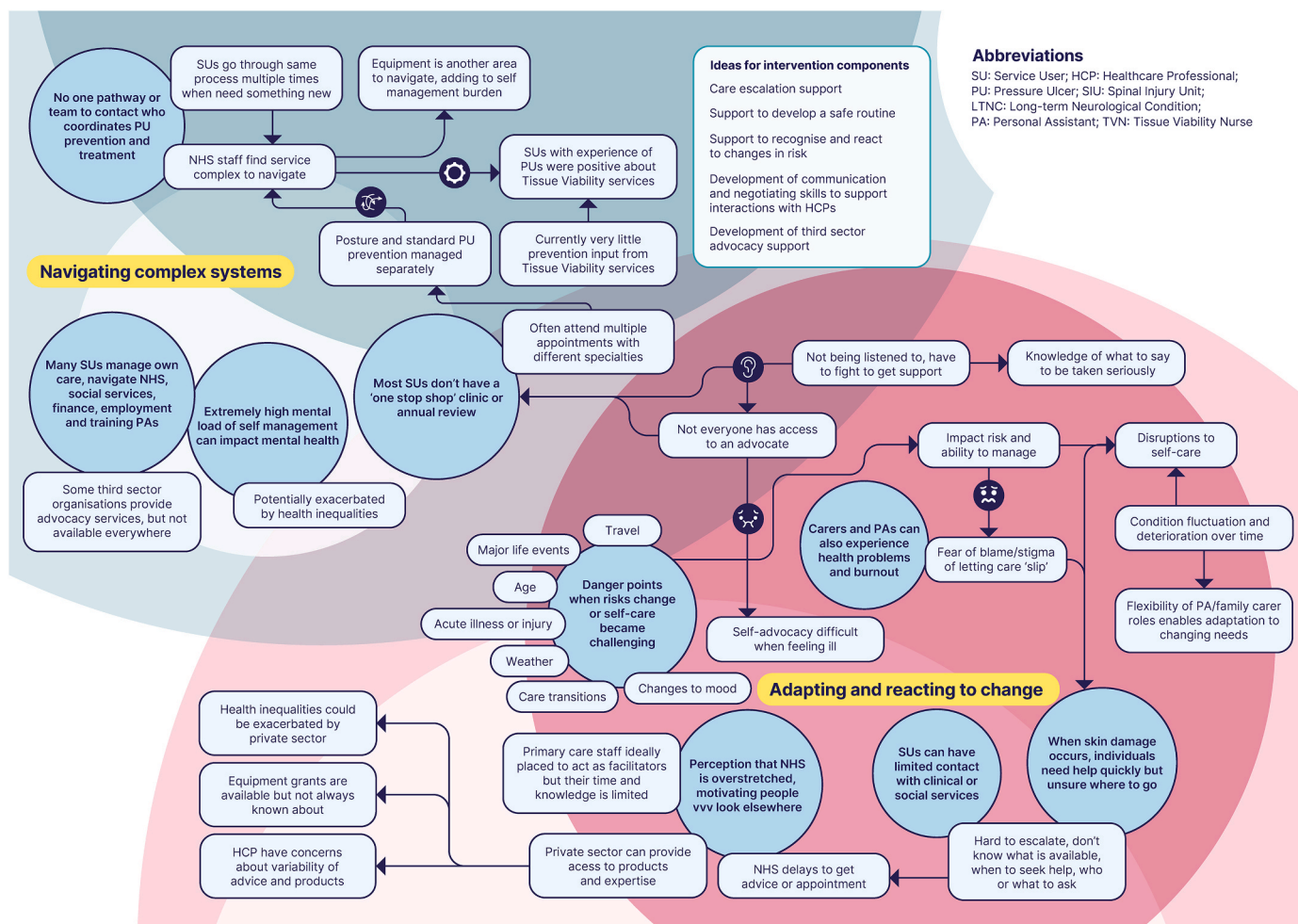


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Conversations about risk can be complex and challenging and require strong communication skills for SUs and HCPs. Some SUs described a power imbalance, making communication and risk negotiation more challenging. They wanted to be able to negotiate on a more even footing.

5.8. Supporting roles

SUs noted a gap in the provision of hands-on, face-to-face care in the home provided by the NHS. A gap that was often filled by informal carers and PAs.

5.8.1. Informal carers

There was a diverse approach to family involvement in care. Where family support was an option, some SUs preferred to keep their family relationships separate from their personal care needs. However, many people indicated the vital support and advocacy provided by family members who were often involved in PU prevention/treatment activities. Participants noted the positive and negative impact this had on family dynamics. Many spoke about the beneficial impact that caring had on their relationship:

‘... I think that’s part of what it’s about as well, being able to contribute, not just feeling like [name of family carer] is doing everything for me and I am actually able to give back and it does help with our relationship. He’s fantastic, he will just keep going and he knows that it’s not that I’ve chosen to be ill. That’s what he always

says to me, “x, you’ve not chosen this, this is not a choice you’ve made and we’ve just got to work with it.” (Service user)

However, some carers spoke of feeling overwhelmed, with several people describing the long term, negative impact the role had on their mental health, which some felt was inextricably linked with the mental health of the person they support.

“It’s easy for that to be a spiral isn’t it ... because if you’re the care giver and not in a good place mentally, you know, the person you care for might not be grateful and that then has an impact on your mental health, making it more difficult to deliver the care ... and then equally that can spiral, that you’re both spinning off one another” (Carer)

People also described feeling guilty when the person they cared for developed a PU, even if they were not equipped with the knowledge and skills to support prevention at that time.

5.8.2. PAs

Most PAs did not currently see PU prevention as part of their role. However, they recognised that they may be well placed to notice skin damage or changes in risk. Some described feeling like part of the family they supported, developing close, trusting relationships. PAs also felt a significant responsibility for their clients. Despite this, PAs are often not included in multi-disciplinary meetings about care needs. The PA employment context is complex and has an impact on the care provided with PAs acknowledging a need for more support and guidance e.g.

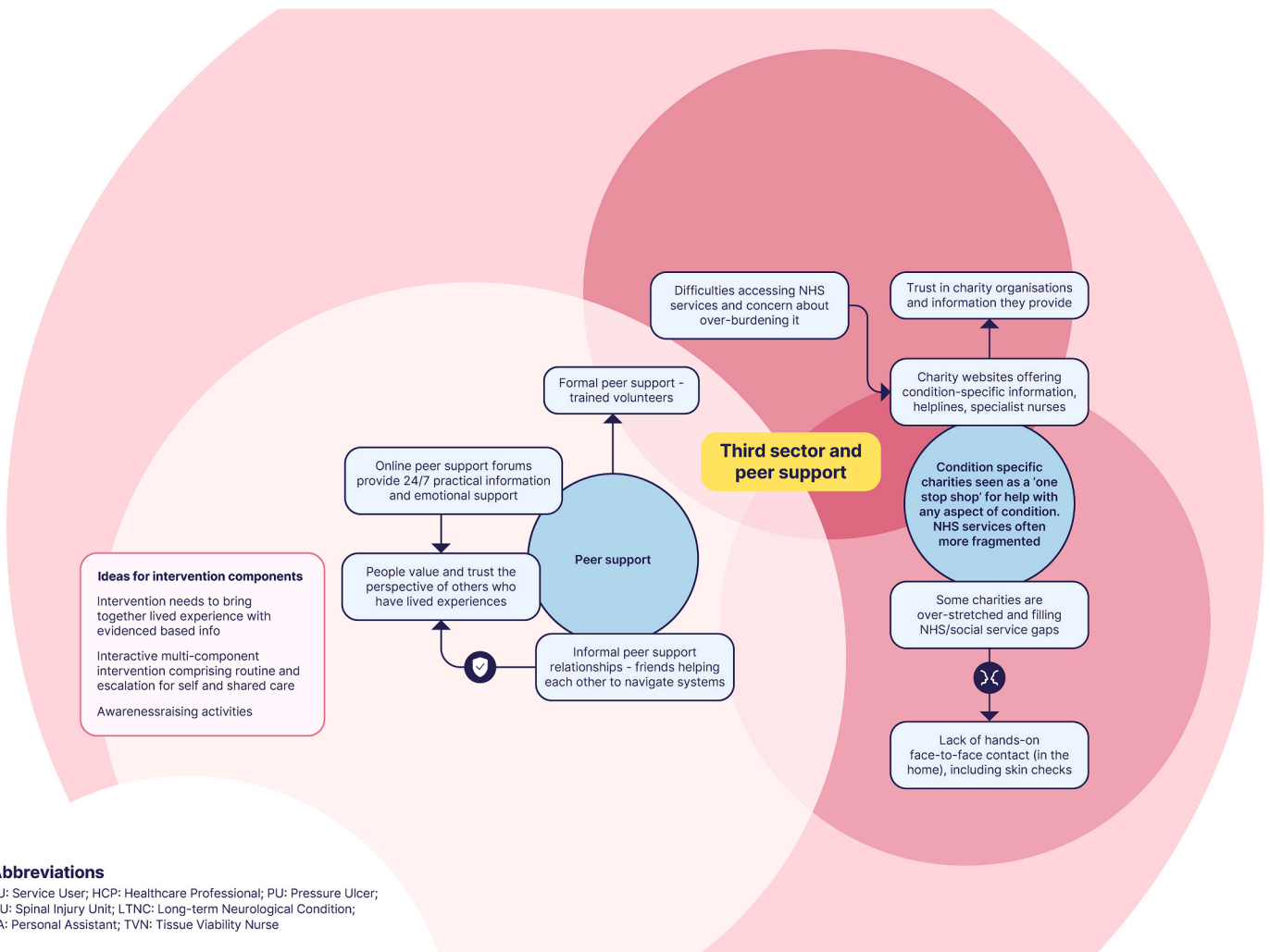


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around role negotiation, boundary setting, and challenging conversations.

5.9. Intervention components and Theory of Change

Our findings identified the need for an engaging, interactive, multi-component intervention to support the needs of people with LTNCs, their informal carers, PAs and HCPs comprising.

1. Awareness raising materials about PU risk and prevention.
2. Support to develop and implement a personalised safe routine and how to react to changes in risk.
3. Care escalation guidance.
4. A framework to support risk communication and negotiation between stakeholders (e.g. SUs and HCPs).

The ToC (Fig. 3) illustrates the intervention components and the causal pathway to achieve change and real-world impact.

6. Discussion

We used a novel participatory approach to gain a deeper understanding of the experiences of people with LTNC, their informal, carers, PAs and professionals in preventing and managing PU risk, in order to identify how improvements can be made to existing activities and

services. Our findings indicate that people with LTNCs experience challenges to accessing information, negotiating single specialty services, inclusion in shared decision-making, and as a result, PU prevention. These challenges are compounded by fatigue, cognitive difficulties and wider contextual social responsibilities. The complexities of managing PU risk while maintaining a good quality of life impacts individuals and those supporting them, including family, informal carers and PAs [40,41]. These relationships are pivotal in supporting people at home.

The ability to self-advocate appears to be a vital yet undervalued skill for this population. Advocates, such as family members and PAs, also play a vital role in accessing appropriate NHS support but some people with LTNC do not have this available to them. We recognise this as a potential barrier for our future intervention development and evaluation work. In keeping with the findings of others, the increasing complexity of health and care systems (in terms of treatments, knowledge, specialisation, and technology) has also made it difficult for people to navigate systems, resulting in an ongoing high treatment burden [42–47]. This is exacerbated in this population by several important factors including: wider complex needs, cognitive difficulties and multiple co-morbidities [1,44,48]; pressure ulcers being a cross specialty issue [4,49]; and acknowledged health inequalities associated with disability and other characteristics [50–53].

When people can access services, they sometimes experience difficult interactions with HCPs relating to the different ways SUs and HCPs

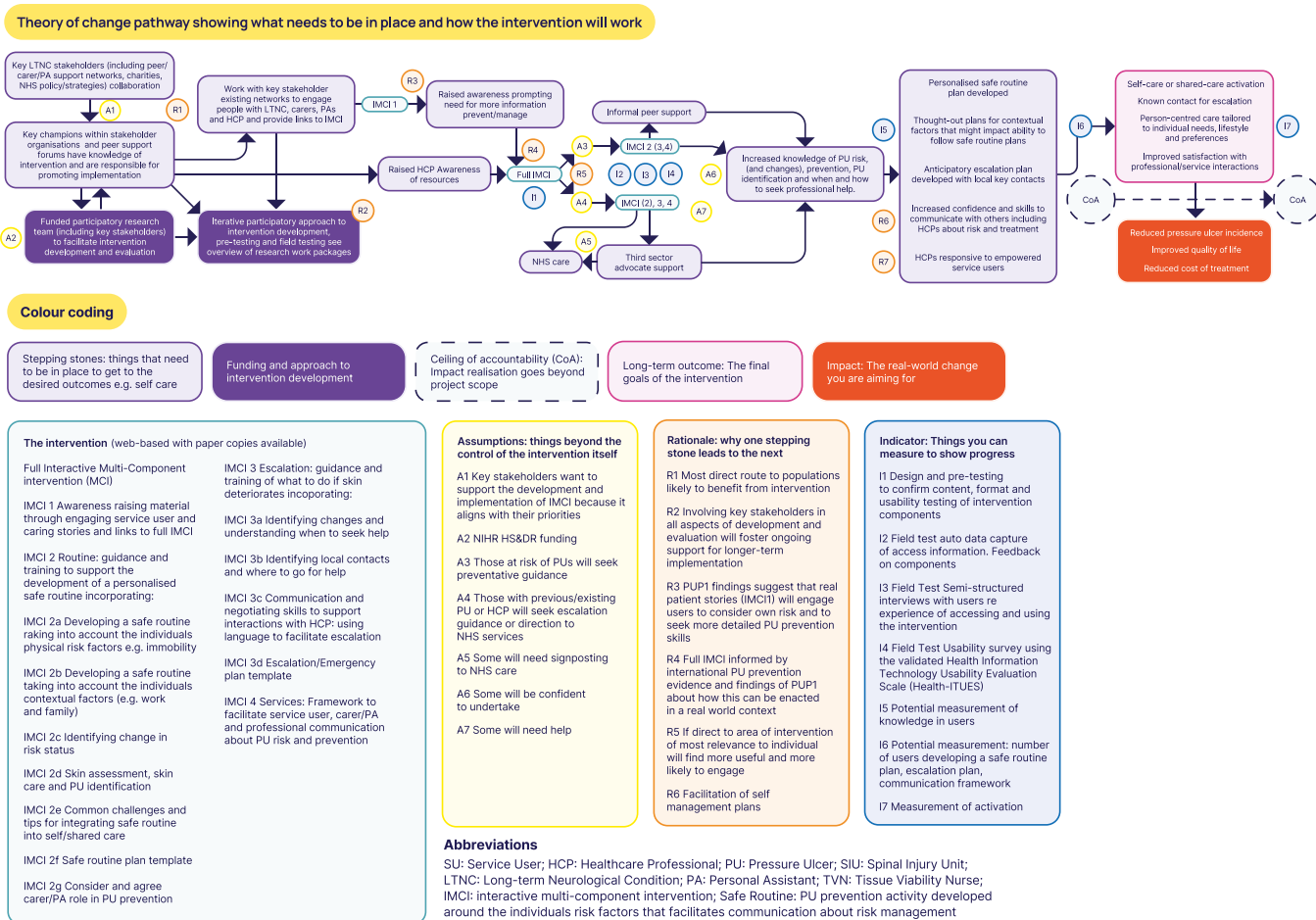


Fig. 3. Theory of Change

perceive PU risk and its management [54–56]. Our study reinforces that SUs perceptions of risk are influenced by their first-hand experience (or lack of) of having a PU, or knowledge shared by those who have [55,56]. They consider PU risk and self-management within the wider context of their everyday life. This incorporates consideration of other health-related risks, as well as meeting the requirements of their wider roles and responsibilities in society, such as work, family and caring. This can create tension as they try to balance PU prevention activities (i. e. pressure relief sometimes involving periods of bedrest) with an active and fulfilling quality of life [41,55,57].

Balancing effective PU prevention and quality of life requires a flexible approach, and this was not universally encountered in our participants’ interactions with HCPs and services. At times, this was related to HCPs concerns about deviating from ‘best practice’ due to fears of blame and/or litigation if things went wrong. This resonates with another study which found nurses reported concerns about getting ‘things wrong’ in PU prevention and subsequent risk aversion, particularly in those with less experience [58]. Work in other areas also concurs with this, where less experienced doctors were more risk averse and had increased difficulty dealing with uncertainty, impacting clinical decision making (e.g. ordering more tests to reduce uncertainty) [59]. This is likely compounded if HCPs have concerns about the SU’s cognitive ability and level of understanding around the risks and benefits. It could explain why HCPs are more inclined to stick rigidly to best practice guidance and why SUs are often willing to accept elevated levels of risk that some HCPs are not comfortable with.

These differing perceptions of PU risk and prevention make conversations about risk between SUs, carers and HCPs difficult, yet our

findings and those of others [55,57,60] suggest these need to occur to develop PU prevention activities which can be tailored to individual need, lifestyle and preferences, making adequate prevention more likely. These challenges may also be influenced by power imbalances and epistemic injustice, where in the context of PU prevention, clinical training and expertise are more highly valued than the lived experience [61,62]. This is supported by a previous study investigating why some people develop severe PUs, that found SU concerns were often not listened to and that people were blamed when ulcers developed [19]. This issue is more complex than simply improving communication within clinical consultations. Healthcare systems are often hierarchical in nature, with policies and culture that make it harder for HCPs to work in genuine partnership with the people they support [47]. In addition, SUs may not have access to support or resources which encourage them to make sense of, value, and communicate their own expertise. Our future intervention will include PU care escalation guidance, however more work is needed to ensure that services meet the needs of people with LTNCs and respond to empowered, informed users as well as providing proactive support to people who are not.

7. Conclusions

Using a participatory approach and including a range of important stakeholders we have uncovered the complexities of managing PU prevention activities at home for people with LTNC, their carers and PAs. This is set within a context of SUs managing multiple care needs and having wider roles in their families and society, as well as other challenges such as fatigue and cognitive difficulties, necessitating a flexible

approach to PU prevention.

Our findings uncovered some positive ways SUs, carers, PA and HCP managed PU risk and prevention, as well as areas of tension in the system. These are illustrated in a systems map which helped us to consider and discuss areas that are amenable to change and to identify future intervention components. These relate to: awareness raising materials; support to develop a personalised safe routine; care escalation guidance; and a framework to support risk communication and negotiation between SUs, carers, PAs and HCPs and are situated in a ToC showing the causal pathway needed to make real world change and improvement. The valuable stakeholder relationships developed through this research will underpin planned development and evaluation work for an interactive, multi-component intervention to support this population in PU prevention.

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Declaration of competing interest

No conflict of interest have been declared by the authors.

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Appendix A. Supplementary data

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References

- [1] NA. *The long term plan for the NHS: Getting it right for neurology patients*, N. Alliance. <https://www.neural.org.uk/assets/pdfs/2018-08-long-term-plan-for-nhs.pdf>; 2018.
- [2] DH. The NHS long term plan. DH, <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>; 2019.
- [3] TVSCN. In: Network TVSC, editor. TRANSFORMING COMMUNITY NEUROLOGY what commissioners need to know Part A – transformation guide; 2016. <http://tvs.cn.nhs.uk/wp-content/uploads/2016/06/Transforming-Community-Neurology-Part-A-Transformation-Guide-version-1.pdf>.
- [4] Coleman S, et al. Patient risk factors for pressure ulcer development: systematic review. *Int J Nurs Stud* 2013;50(7):974–1003.
- [5] Coleman S, et al. A new pressure ulcer conceptual framework. *J Adv Nurs* 2014;70(10):2222–34.
- [6] Shiferaw WS, et al. The global burden of pressure ulcers among patients with spinal cord injury: a systematic review and meta-analysis. *BMC Musculoskel Disord* 2020; 21(1):334.
- [7] Briggs M, et al. The prevalence of pain at pressure areas and pressure ulcers in hospitalised patients. *BMC Nurs* 2013;12(1):19. <http://www.biomedcentral.com/1472-6955/12/19>.
- [8] Smith IL, et al. Pressure ulcer and wounds reporting in NHS hospitals in England part 1: audit of monitoring systems. *J Tissue Viability* 2016;25(1):3–15.
- [9] McGinnis E, et al. Pressure ulcer related pain in community populations: a prevalence survey. *BMC Nurs* 2014;13:16.
- [10] Vowden KR, Vowden P. The prevalence, management, equipment provision and outcome for patients with pressure ulceration identified in a wound care survey within one English health care district. *J Tissue Viability* 2009;18(1):20–6.
- [11] Wong JK, Amin K, Dumville JC. Reconstructive surgery for treating pressure ulcers. *Cochrane Database Syst Rev* 2016;12(12):CD012032. CD012032.
- [12] Kortebein P, et al. Functional impact of 10 days of bed rest in healthy older adults. *The journals of gerontology. Series A, Biological sciences and medical sciences* 2008;63(10):1076–81.
- [13] Berlowitz D, et al. Preventing Pressure Ulcers in hospitals: a toolkit for improving quality of care. 2011. AHRQ (Agency for Healthcare Research Quality).
- [14] Dealey C, Posnett J, Walker A. The cost of pressure ulcers in the United Kingdom. *J Wound Care* 2012;21(6):261–6.
- [15] Schuurman J-P, et al. Economic evaluation of pressure ulcer care: a cost minimization analysis of preventive strategies. *Nurs Econ* 2009;27(6):390–400.
- [16] Severens JL, et al. The cost of illness of pressure ulcers in The Netherlands. *Adv Skin Wound Care* 2002;15(2):72–7.
- [17] Bennett G, Dealey C, Posnett J. The cost of pressure ulcers in the UK. *Age Ageing* 2004;33(3):230–5.
- [18] Guest JF, et al. Cohort study evaluating pressure ulcer management in clinical practice in the UK following initial presentation in the community: costs and outcomes. *BMJ Open* 2018;8(7):e021769.
- [19] Pinkney L, et al. Why do patients develop severe pressure ulcers? A retrospective case study. *BMJ Open* 2014;4(1). <http://bmjopen.bmj.com/content/4/1/e004303.full.pdf>.
- [20] Jagosh J, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90.
- [21] Leask CF, et al. Framework, principles and recommendations for utilising participatory methodologies in the co-creation and evaluation of public health interventions. *Research Involvement and Engagement* 2019;5(1):2.
- [22] J., H.. Co-operative Inquiry, research into the human condition. London: Sage; 1996.
- [23] Abma T. Participatory research for health and social well-being. S. Switzerland Singer. 2019.
- [24] Nierse CJ, et al. Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team. *Health Expect : an international journal of public participation in health care and health policy* 2012;15(3):242–54.
- [25] Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995;311(7000): 299–302.
- [26] Leung FH, Savithiri R. Spotlight on focus groups. *Can Fam Physician* 2009;55(2): 218–9.
- [27] CECAN. Participatory systems mapping: a practical guide. (accessed 2. February.21).
- [28] BurnsD. Participatory systemic inquiry. *IDS Bull* 2012;43(3):88–100. <https://doi.org/10.1111/j.1759-5436.2012.00325.x>.
- [29] Maani KE, Cavana RY. Systems thinking, system dynamics: managing change and complexity. second ed. New Zealand: Pearson Education New Zealand; 2007.
- [30] De Savigny D, Adam T. Systems thinking for health systems strengthening. World Health Organization; 2009.
- [31] De Silva MJ, et al. Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. *Trials* 2014;15: 267.
- [32] Breuer E, et al. Using theory of change to design and evaluate public health interventions: a systematic review. *Implement Sci* 2016;11(1):63.
- [33] Coleman SMD, McLarty L, Stubbs N, Sandoz H, Drinkwater J, Ledger L, Nixon J, Birks Y, Holland C, Rawson Y. McGoverin , A *pressure ulcer Prevention at home protocol*. <https://njl-admin.nihr.ac.uk/document/download/2041918>; 2022.
- [34] Delia Muir, L.M., Jessica Drinkwater, Carole Bennett, Yvonne Birks, Andrea Broadway-Parkinson, Vanessa Cooksey, Phil Gleeson, Christy Holland, Lisa Ledger, Daniella-Jade Lowe, Andrea McGoverin, Jane Nixon, Chanya Perry, Heidi Sandoz, Brian Rawson, Yvonne Rawson, Nikki Stubbs, Kay Walker, Helen Whitaker, Susanne Coleman, Synopsis: pressure ulcer prevention at home (PUP@home) for people with long-term neurological conditions, Carers and personal assistants: a participatory qualitative study. . NIHR Journals Library, submitted for publication.
- [35] NCCPE. Community-based participatory research A guide to ethical principles and practice. National Co-ordinating Centre for Public Engagement: Durham University; 2012. https://www.publicengagement.ac.uk/sites/default/files/publication/cbpr_ethics_guide_web_november_2012.pdf.
- [36] Muskat M, Muskat B, Zehrer A, Johns R. Mobile ethnography as an emerging research method. In: BAM2013. British Academy of Management; 2013.
- [37] Vindrola-Padros C, et al. Carrying out rapid qualitative research during a pandemic: emerging lessons from COVID-19. *Qual Health Res* 2020;30(14): 2192–204.
- [38] MuirD Public. Involvement in qualitative research. In: Brooks J, editor. *Applied Qualitative Research in Psychology*, K.N.e; 2017. Palgrave Basingstoke.
- [39] Baxter S, et al. Evaluating public involvement in research design and grant development: using a qualitative document analysis method to analyse an award scheme for researchers. *Res Involv Engagem* 2016;2:13.
- [40] uk C. State of caring. https://www.carersuk.org/media/xgwj0gn/soc23-health-report_web.pdf; 2023.
- [41] Roddis J, et al. Barriers and facilitators to pressure ulcer prevention behaviours by older people living in their own homes and their lay carers: a qualitative study. *BMJ Open* 2024;14(3):e080398.
- [42] May C, et al. Rethinking the patient: using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res* 2014;14.
- [43] Plesek P, Greenhalgh T. Complexity science: the challenge of complexity in health care. *BMJ* 2001;323.
- [44] Haggerty JL. Ordering the chaos for patients with multimorbidity. *BMJ* 2012;345: e5915.
- [45] Gui X, Chen Y, Pine KH. Navigating the healthcare service "black box": individual competence and fragmented system. *Proc. ACM Hum.-Comput. Interact.* 2018;2 (CSCW). Article 61.

- [46] Griese L, et al. Challenges in navigating the health care system: development of an instrument measuring navigation health literacy. *Int J Environ Res Public Health* 2020;17(16).
- [47] Montori VM. Turning away from industrial health care toward careful and kind care. *Acad Med* 2019;94(6):768–70.
- [48] Kuluski K, et al. Community care for people with complex care needs: bridging the gap between health and social care. *Int J Integr Care* 2017;17(4):2.
- [49] Guest JF, et al. Health economic burden that wounds impose on the National Health Service in the UK. *BMJ Open* 2015;5(12).
- [50] Ona A, et al. Unmet healthcare needs and health inequalities in people with spinal cord injury: a direct regression inequality decomposition. *Int J Equity Health* 2023; 22(1):56.
- [51] WHO. Disability. accessed 2024. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>: WHO.
- [52] Healthwatch. Third of people in England lack confidence they can access critical NHS services. 2023 30/7/24.
- [53] Veena R. The health of people from ethnic minority groups in England. 2021. 30/7/2024.
- [54] Ledger L, et al. Patient involvement in pressure ulcer prevention and adherence to prevention strategies: an integrative review. *Int J Nurs Stud* 2020;101:103449.
- [55] Ledger LJ, et al. Patient perceptions and understanding of pressure ulcer risk in the community: empirical Research Qualitative. *J Adv Nurs* 2023;79(9):3312–23.
- [56] Coleman SMD, Rawson B, Rawson Y. Patient involvement in risk tool development. *Nursing Times* 2015;111(25):17–9.
- [57] Soegaard K, et al. "I am just trying to live a life!" -a qualitative study of the lived experience of pressure ulcers in people with spinal cord injuries. *J Tissue Viability* 2024;33(1):50–9.
- [58] Coleman S, et al. Using PURPOSE-T in clinical practice: a realist evaluation. *J Tissue Viability* 2024.
- [59] Lawton R, et al. Are more experienced clinicians better able to tolerate uncertainty and manage risks? A vignette study of doctors in three NHS emergency departments in England. *BMJ Qual Saf* 2019;28(5):382–8.
- [60] Shanley E, et al. The impact of the Shanley Pressure Ulcer Prevention Programme on older persons' knowledge of, and attitudes and behaviours towards, pressure ulcer prevention. *Int Wound J* 2022;19(4):754–64.
- [61] Havi Carel IJK. *Epistemic injustice in medicine and healthcare*, 1. Routledge; 2017. <https://www.taylorfrancis.com/chapters/edit/10.4324/9781315212043-33/epistemic-injustice-medicine-healthcare-havi-carel-ian-james-kidd>.
- [62] Fricker M. *Epistemic injustice: power and the Ethics of knowing*. Oxford University Press; 2007.