Article:

Muir, Delia, McLarty, Laura, Drinkwater, Jessica et al. (2 more authors) (2024) Pressure ulcer prevention for people with long-term neurological conditions (LTNCs) who self-manage care and live at home. Journal of tissue viability. pp. 753-765. ISSN 0965-206X

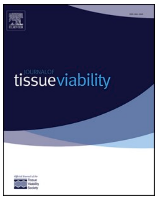
https://doi.org/10.1016/j.jtv.2024.08.007

Journal of Tissue Viability 33 (2024) 753–765

Contents lists available at ScienceDirect

Journal of Tissue Viability

journal homepage: www.elsevier.com/locate/jtv



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

Delia Muir [a], Laura McLarty [a], Jessica Drinkwater [b], Carole Bennett [c], Yvonne Birks [d], Andrea Broadway-Parkinson [c], Vanessa Cooksey [c], Phil Gleeson [c], Christy Holland [e], Lisa Ledger [f], Daniella-Jade Lowe [c], Andrea McGoverin [c], Jane Nixon [g], Tanya Perry [c], Heidi Sandoz [c], Brian Rawson [c], Yvonne Rawson [h], Nikki Stubbs [i], Kay Walker [c], Helen Whitaker [c], Susanne Coleman [a,*]

[a] *Leeds Institute of Clinical Trials Research, University of Leeds, Leeds, LS2 9JT, UK*
[b] *Centre for Primary Care and Health Service Research, The University of Manchester, UK*
[c] *Pressure Ulcer at Home Co-operative Inquiry Group, UK*
[d] *School for Business and Society, University of York, UK*
[e] *Leeds Community Healthcare Trust, UK*
[f] *NIHR Coordinating Centre, 21 Queen Street, Leeds, LS1 2TW, UK*
[g] *Institute of Health Sciences, University, of Leeds, Leeds, LS2 9JT, UK*
[h] *Tissue Viability CNS, Hertfordshire Community NHS Trust, UK*
[i] *Independent Tissue Viability Nurse, UK*

ARTICLE INFO

Keywords:
Pressure ulcer prevention
Long term neurological conditions
Community
Self-management
Participatory research
Systems mapping
Qualitative

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.

---

* Corresponding author.
E-mail addresses: D.P.Muir@leeds.ac.uk (D. Muir), s.b.coleman@leeds.ac.uk (S. Coleman).

https://doi.org/10.1016/j.jtv.2024.08.007
Received 31 July 2024; Accepted 23 August 2024

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 LTCNs 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.

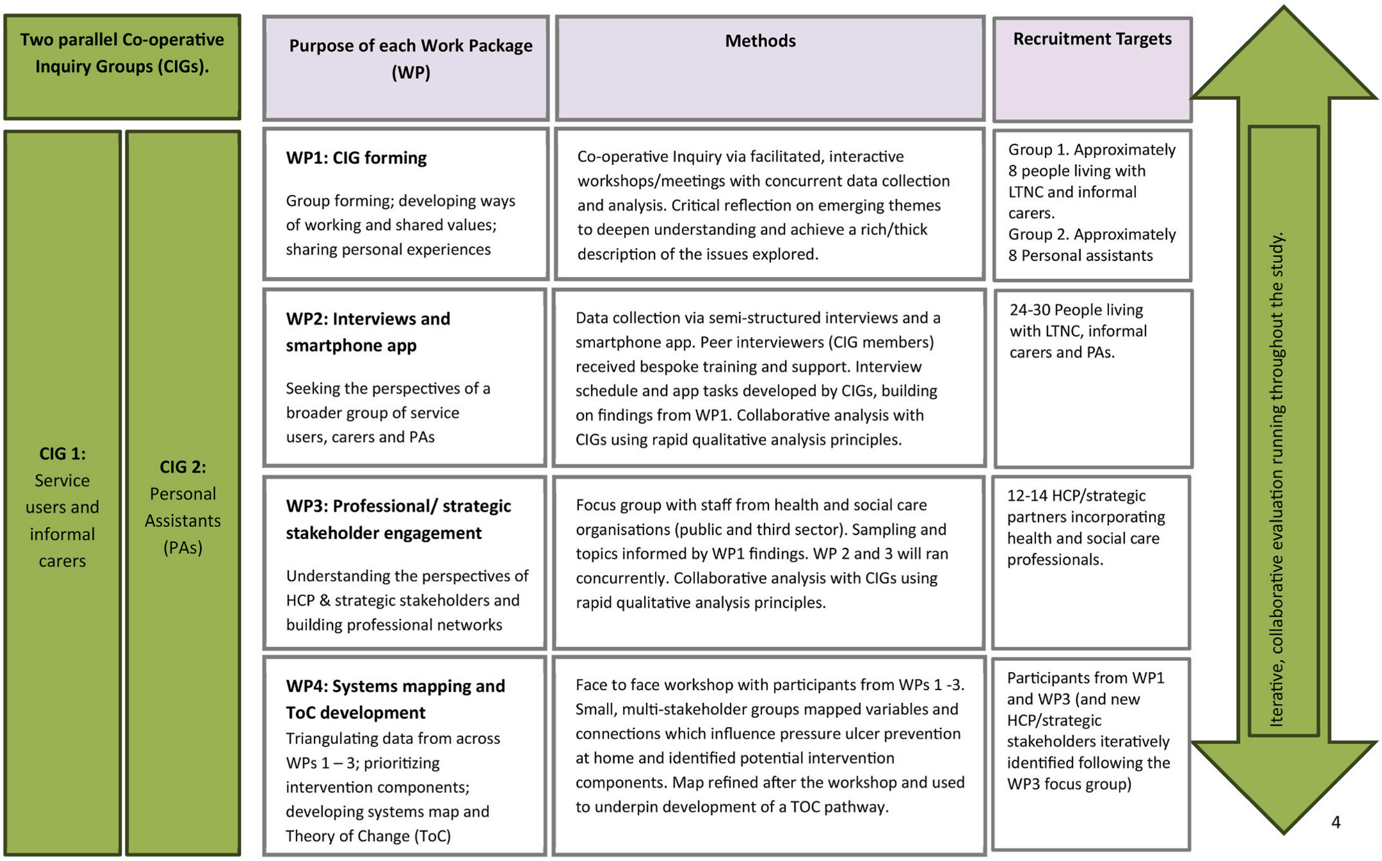
2. Aims and Objectives

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.



Two parallel Co-operative Inquiry Groups (CIGs).	Purpose of each Work Package (WP)	Methods	Recruitment Targets
CIG 1: Service users and informal carers **CIG 2:** Personal Assistants (PAs)	**WP1: CIG forming** Group forming; developing ways of working and shared values; sharing personal experiences	Co-operative Inquiry via facilitated, interactive workshops/meetings with concurrent data collection and analysis. Critical reflection on emerging themes to deepen understanding and achieve a rich/thick description of the issues explored.	Group 1. Approximately 8 people living with LTNC and informal carers. Group 2. Approximately 8 Personal assistants
	WP2: Interviews and smartphone app Seeking the perspectives of a broader group of service users, carers and PAs	Data collection via semi-structured interviews and a smartphone app. Peer interviewers (CIG members) received bespoke training and support. Interview schedule and app tasks developed by CIGs, building on findings from WP1. Collaborative analysis with CIGs using rapid qualitative analysis principles.	24-30 People living with LTNC, informal carers and PAs.
	WP3: Professional/ strategic stakeholder engagement Understanding the perspectives of HCP & strategic stakeholders and building professional networks	Focus group with staff from health and social care organisations (public and third sector). Sampling and topics informed by WP1 findings. WP 2 and 3 will ran concurrently. Collaborative analysis with CIGs using rapid qualitative analysis principles.	12-14 HCP/strategic partners incorporating health and social care professionals.
	WP4: Systems mapping and ToC development Triangulating data from across WPs 1 – 3; prioritizing intervention components; developing systems map and Theory of Change (ToC)	Face to face workshop with participants from WPs 1 -3. Small, multi-stakeholder groups mapped variables and connections which influence pressure ulcer prevention at home and identified potential intervention components. Map refined after the workshop and used to underpin development of a TOC pathway.	Participants from WP1 and WP3 (and new HCP/strategic stakeholders iteratively identified following the WP3 focus group)

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 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 oversite 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

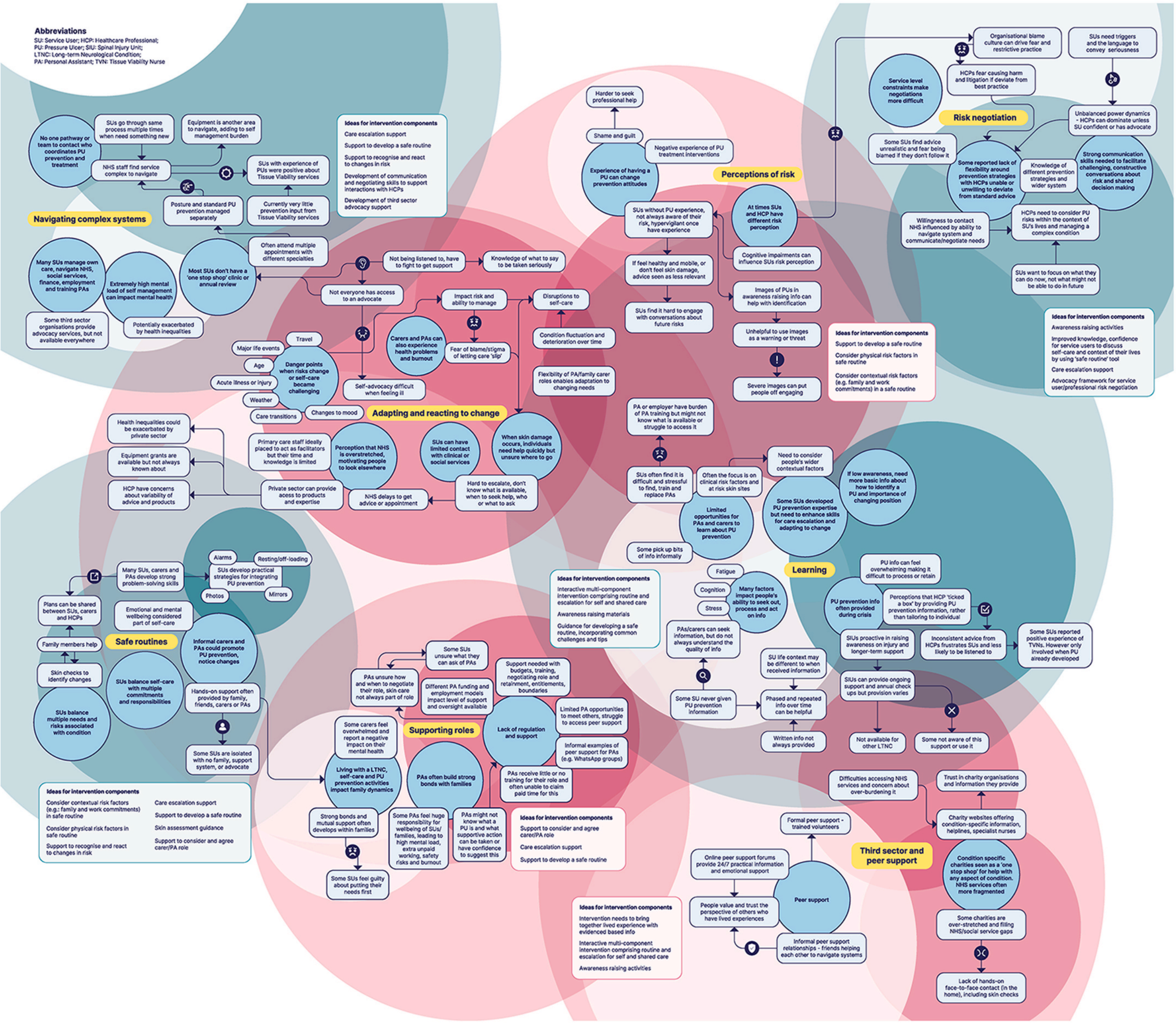
Participants shared varying experiences of PU prevention learning and support. Some reported never receiving (or not remembering) any information about PU prevention or that they only became aware of their PU risk through involvement in this study. Those participants emphasised the need for PU awareness 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



Abbreviations
SU: Service User; HCP: Healthcare Professional;
PU: Pressure Ulcer; SIU: Spinal Injury Unit;
LTNC: Long-term Neurological Condition;
PA: Personal Assistant; TVN: Tissue Viability Nurse

Navigating complex systems

No one pathway or team to contact who coordinates PU prevention and treatment
SUs go through same process multiple times when need something new
Equipment is another area to navigate, adding to self management burden
NHS staff find service complex to navigate
SUs with experience of PUs were positive about Tissue Viability services
Posture and standard PU prevention managed separately
Currently very little prevention input from Tissue Viability services
Often attend multiple appointments with different specialties
Many SUs manage own care, navigate NHS, social services, finance, employment and training PAs
Extremely high mental load of self management can impact mental health
Most SUs don't have a 'one stop shop' clinic or annual review
Some third sector organisations provide advocacy services, but not available everywhere
Potentially exacerbated by health inequalities

Ideas for intervention components
Care escalation support
Support to develop a safe routine
Support to recognise and react to changes in risk
Development of communication and negotiating skills to support interactions with HCPs
Development of third sector advocacy support

Perceptions of risk

Harder to seek professional help
Shame and guilt
Negative experience of PU treatment interventions
Experience of having a PU can change prevention attitudes
SUs without PU experience, not always aware of their risk, hypervigilant once have experience
At times SUs and HCP have different risk perception
Cognitive impairments can influence SUs risk perception
If feel healthy and mobile, or don't feel skin damage, advice seen as less relevant
Images of PUs in awareness raising info can help with identification
SUs find it hard to engage with conversations about future risks
Unhelpful to use images as a warning or threat
Severe images can put people off engaging

Ideas for intervention components
Support to develop a safe routine
Consider physical risk factors in safe routine
Consider contextual risk factors (e.g. family and work commitments) in a safe routine

Risk negotiation

Organisational blame culture can drive fear and restrictive practice
SUs need triggers and the language to convey seriousness
Service level constraints make negotiations more difficult
HCPs fear causing harm and litigation if deviate from best practice
Unbalanced power dynamics - HCPs can dominate unless SU confident or has advocate
Some SUs find advice unrealistic and fear being blamed if they don't follow it
Some reported lack of flexibility around prevention strategies with HCPs unable or unwilling to deviate from standard advice
Knowledge of different prevention strategies and wider system
Strong communication skills needed to facilitate challenging, constructive conversations about risk and shared decision making
Willingness to contact NHS influenced by ability to navigate system and communicate/negotiate needs
HCPs need to consider PU risks within the context of SU's lives and managing a complex condition
SUs want to focus on what they can do now, not what might not be able to do in future

Ideas for intervention components
Awareness raising activities
Improved knowledge, confidence for service users to discuss self-care and context of their lives by using 'safe routine' tool
Care escalation support
Advocacy framework for service user/professional risk negotiation

Adapting and reacting to change

Not being listened to, have to fight to get support
Knowledge of what to say to be taken seriously
Not everyone has access to an advocate
Impact risk and ability to manage
Disruptions to self-care
Travel
Major life events
Age
Acute illness or injury
Weather
Care transitions
Changes to mood
Danger points when risks change or self-care became challenging
Carers and PAs can also experience health problems and burnout
Fear of blame/stigma of letting care 'slip'
Condition fluctuation and deterioration over time
Flexibility of PA/family carer roles enables adaptation to changing needs
Self-advocacy difficult when feeling ill
Health inequalities could be exacerbated by private sector
Equipment grants are available but not always known about
HCP have concerns about variability of advice and products
Primary care staff ideally placed to act as facilitators but their time and knowledge is limited
Perception that NHS is overstretched, motivating people to look elsewhere
SUs can have limited contact with clinical or social services
When skin damage occurs, individuals need help quickly but unsure where to go
Private sector can provide acess to products and expertise
NHS delays to get advice or appointment
Hard to escalate, don't know what is available, when to seek help, who or what to ask

Safe routines

Alarms
Resting/off-loading
Many SUs, carers and PAs develop strong problem-solving skills
SUs develop practical strategies for integrating PU prevention
Photos
Mirrors
Plans can be shared between SUs, carers and HCPs
Emotional and mental wellbeing considered part of self-care
Family members help
Skin checks to identify changes
Informal carers and PAs could promote PU prevention, notice changes
SUs balance self-care with multiple commitments and responsibilities
SUs balance multiple needs and risks associated with condition
Hands-on support often provided by family, friends, carers or PAs
Some SUs are isolated with no family, support system, or advocate

Ideas for intervention components
Consider contextual risk factors (e.g.: family and work commitments) in safe routine
Consider physical risk factors in safe routine
Support to recognise and react to changes in risk
Care escalation support
Support to develop a safe routine
Skin assessment guidance
Support to consider and agree carer/PA role

Learning

PA or employer have burden of PA training but might not know what is available or struggle to access it
SUs often find it is difficult and stressful to find, train and replace PAs
Often the focus is on clinical risk factors and at risk skin sites
Need to consider people's wider contextual factors
If low awareness, need more basic info about how to identify a PU and importance of changing position
Limited opportunities for PAs and carers to learn about PU prevention
Some SUs developed PU prevention expertise but need to enhance skills for care escalation and adapting to change
Some pick up bits of info informally
Fatigue
Cognition
Stress
Many factors impact people's ability to seek out, process and act on info
PAs/carers can seek information, but do not always understand the quality of info
PU info can feel overwhelming making it difficult to process or retain
PU prevention info often provided during crisis
Perceptions that HCP 'ticked a box' by providing PU prevention information, rather than tailoring to individual
SIUs proactive in raising awareness on injury and longer-term support
Inconsistent advice from HCPs frustrates SUs and less likely to be listened to
Some SUs reported positive experience of TVNs. However only involved when PU already developed
SU life context may be different to when received information
Some SU never given PU prevention information
Phased and repeated info over time can be helpful
Written info not always provided
SIUs can provide ongoing support and annual check ups but provision varies
Not available for other LTNC
Some not aware of this support or use it

Ideas for intervention components
Interactive multi-component intervention comprising routine and escalation for self and shared care
Awareness raising materials
Guidance for developing a safe routine, incorporating common challenges and tips

Supporting roles

Some SUs unsure what they can ask of PAs
PAs unsure how and when to negotiate their role, skin care not always part of role
Different PA funding and employment models impact level of support and oversight available
Support needed with budgets, training, negotiating role and retainment, entitlements, boundaries
Lack of regulation and support
Limited PA opportunities to meet others, struggle to access peer support
Informal examples of peer support for PAs (e.g. WhatsApp groups)
Some carers feel overwhelmed and report a negative impact on their mental health
Living with a LTNC, self-care and PU prevention activities impact family dynamics
PAs often build strong bonds with families
PAs receive little or no training for their role and often unable to claim paid time for this
Strong bonds and mutual support often develops within families
Some PAs feel huge responsibility for wellbeing of SUs/families, leading to high mental load, extra unpaid working, safety risks and burnout
PAs might not know what a PU is and what supportive action can be taken or have confidence to suggest this
Some SUs feel guilty about putting their needs first

Ideas for intervention components
Support to consider and agree carer/PA role
Care escalation support
Support to develop a safe routine

Third sector and peer support

Difficulties accessing NHS services and concern about over-burdening it
Trust in charity organisations and information they provide
Charity websites offering condition-specific information, helplines, specialist nurses
Formal peer support - trained volunteers
Online peer support forums provide 24/7 practical information and emotional support
Peer support
People value and trust the perspective of others who have lived experiences
Informal peer support relationships - friends helping each other to navigate systems
Condition specific charities seen as a 'one stop shop' for help with any aspect of condition. NHS services often more fragmented
Some charities are over-stretched and filling NHS/social service gaps
Lack of hands-on face-to-face contact (in the home), including skin checks

Ideas for intervention components
Intervention needs to bring together lived experience with evidenced based info
Interactive multi-component intervention comprising routine and escalation for self and shared care
Awareness raising activities

Fig. 2. Systems map overview and clusters.

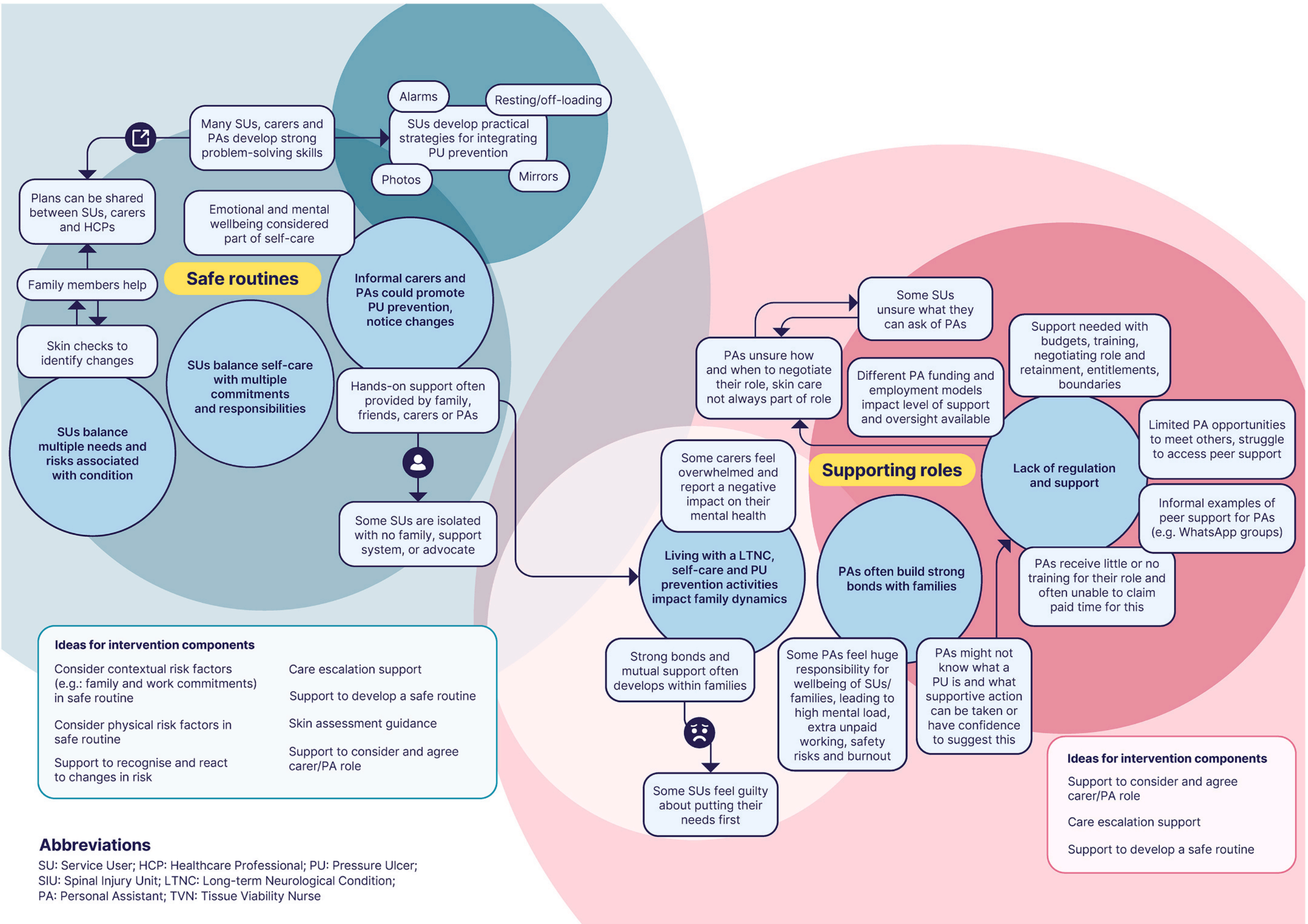


Fig. 2. (*continued*).

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

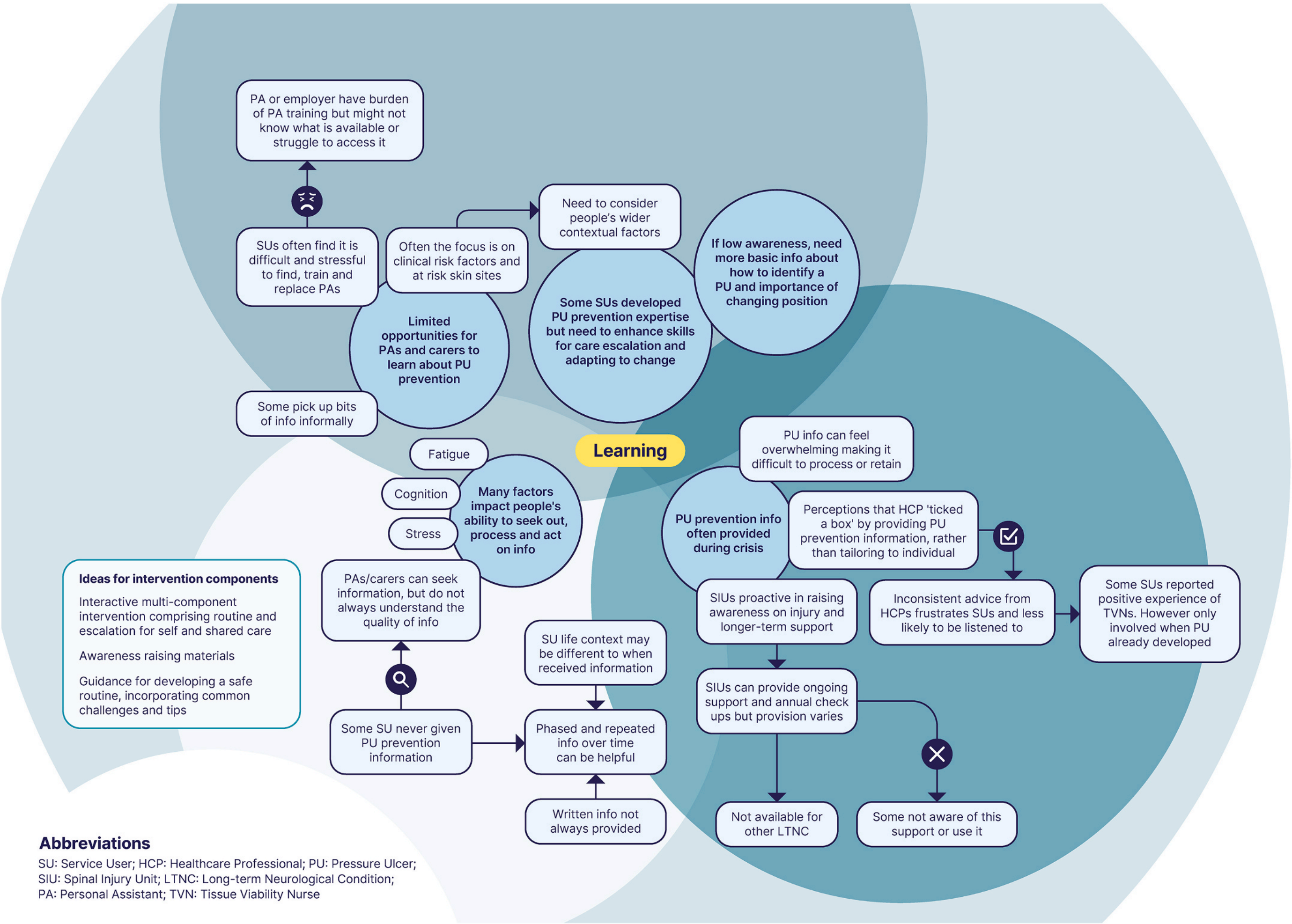


Fig. 2. (*continued*).

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

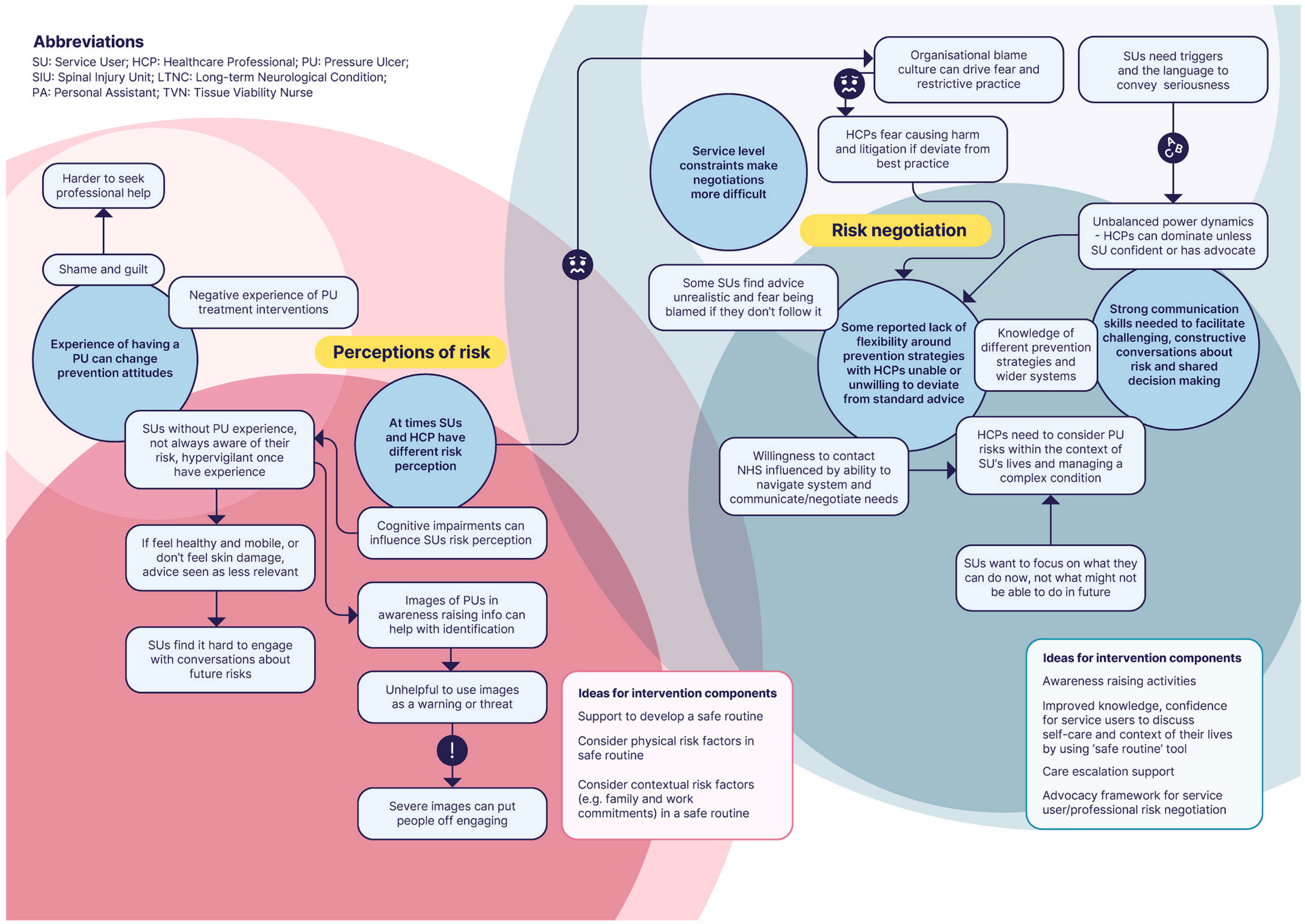


Fig. 2. (*continued*).

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)

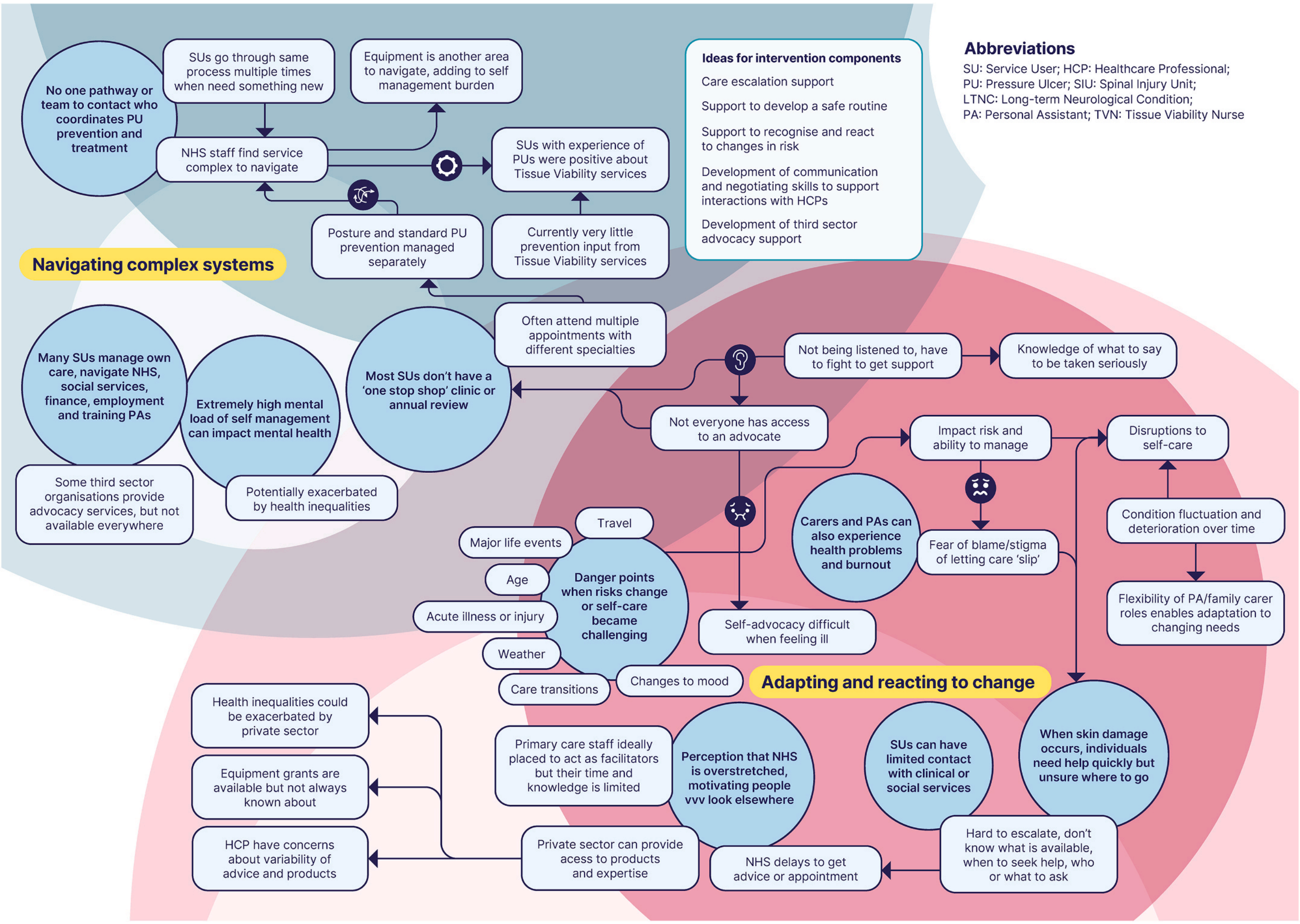


Fig. 2. (*continued*).

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.

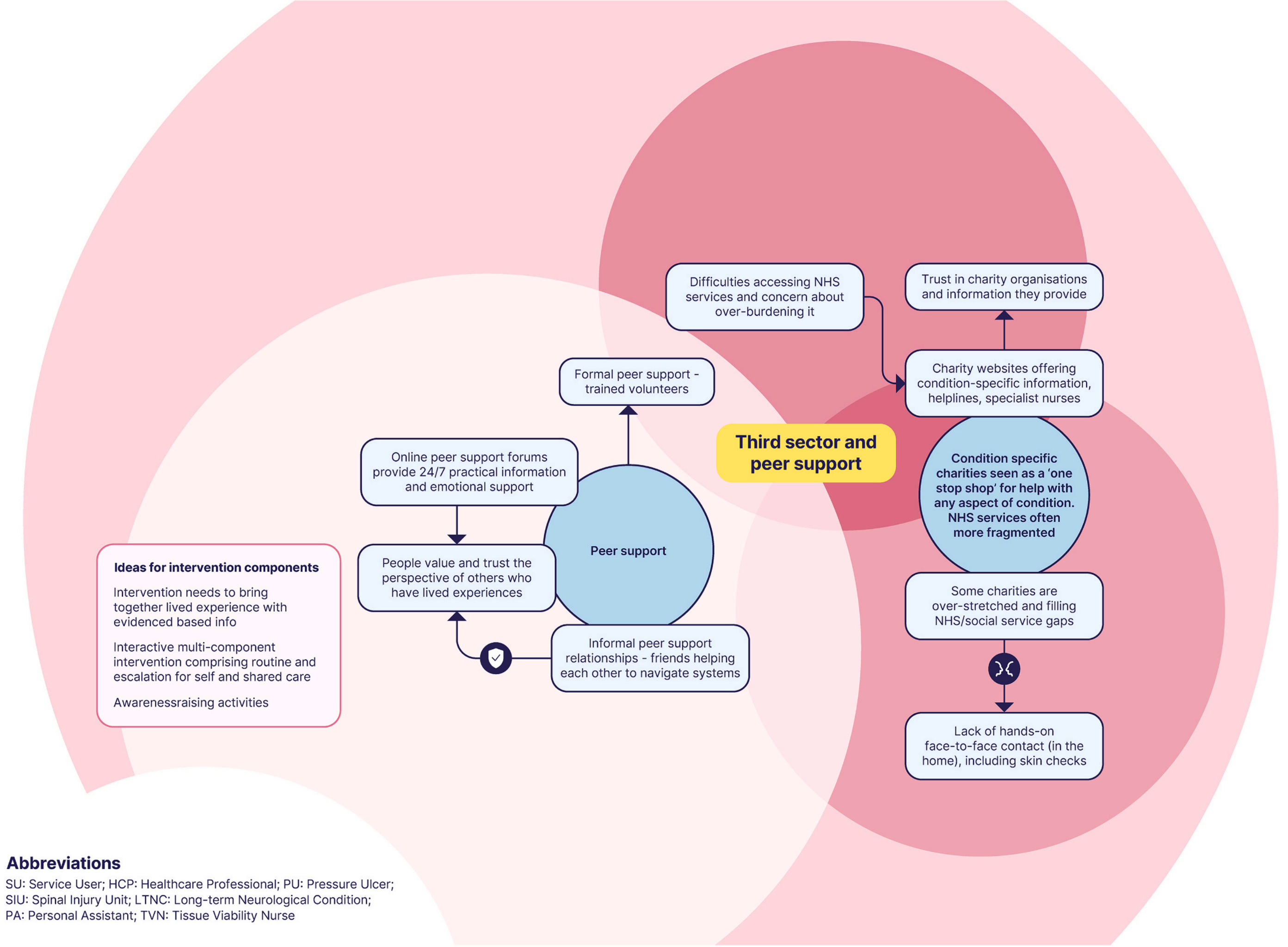


Fig. 2. (*continued*).

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).

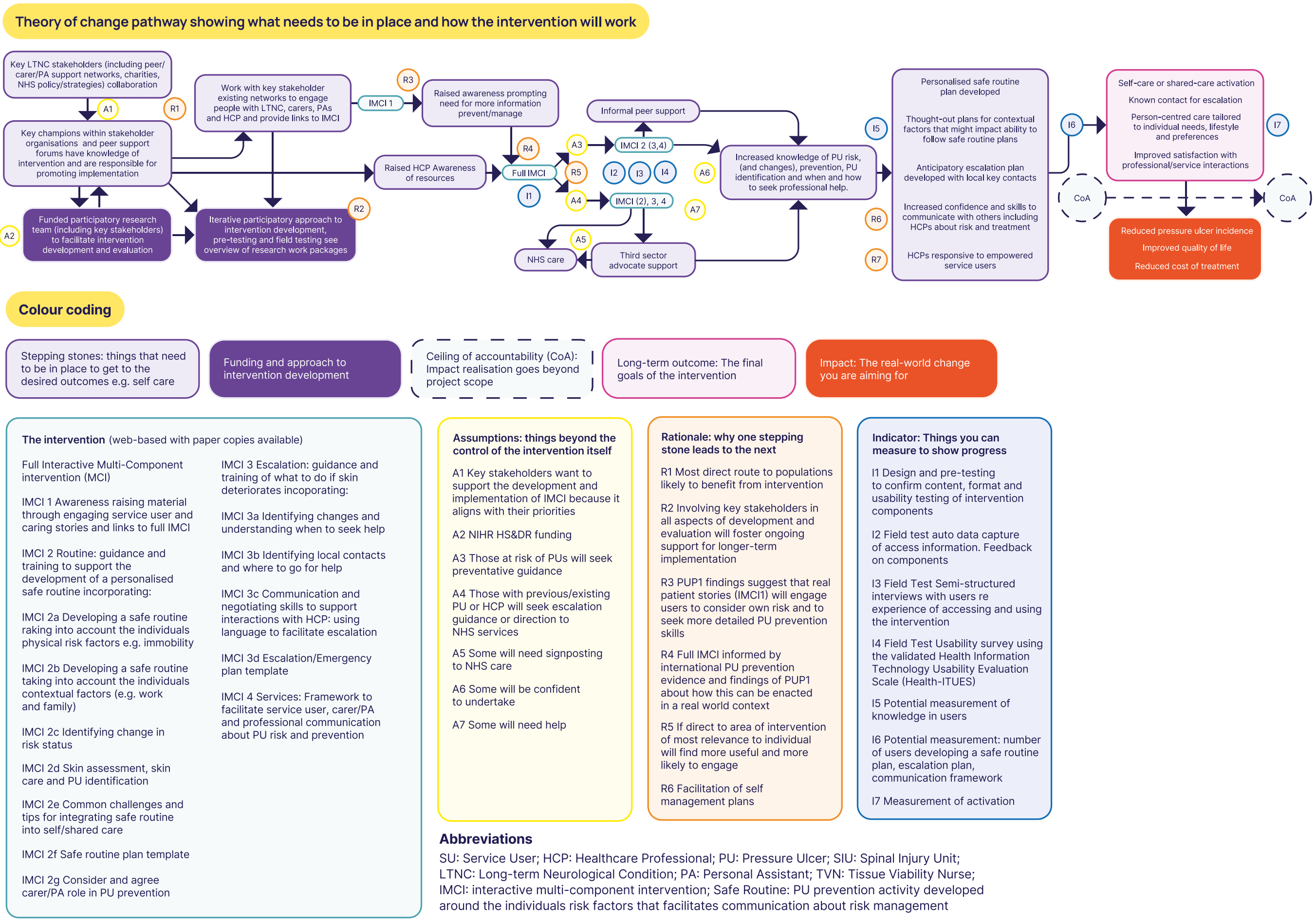
The ToC (Fig. 3) illustrates the intervention components and the causal pathway to achieve change and real-world impact.

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



Stepping stones: things that need to be in place to get to the desired outcomes e.g. self care

Funding and approach to intervention development

Ceiling of accountability (CoA): Impact realisation goes beyond project scope

Long-term outcome: The final goals of the intervention

Impact: The real-world change you are aiming for

The intervention (web-based with paper copies available)

Full Interactive Multi-Component intervention (MCI)

IMCI 1 Awareness raising material through engaging service user and caring stories and links to full IMCI

IMCI 2 Routine: guidance and training to support the development of a personalised safe routine incorporating:

IMCI 2a Developing a safe routine raking into account the individuals physical risk factors e.g. immobility

IMCI 2b Developing a safe routine taking into account the individuals contextual factors (e.g. work and family)

IMCI 2c Identifying change in risk status

IMCI 2d Skin assessment, skin care and PU identification

IMCI 2e Common challenges and tips for integrating safe routine into self/shared care

IMCI 2f Safe routine plan template

IMCI 2g Consider and agree carer/PA role in PU prevention

IMCI 3 Escalation: guidance and training of what to do if skin deteriorates incoporating:

IMCI 3a Identifying changes and understanding when to seek help

IMCI 3b Identifying local contacts and where to go for help

IMCI 3c Communication and negotiating skills to support interactions with HCP: using language to facilitate escalation

IMCI 3d Escalation/Emergency plan template

IMCI 4 Services: Framework to facilitate service user, carer/PA and professional communication about PU risk and prevention

Assumptions: things beyond the control of the intervention itself

A1 Key stakeholders want to support the development and implementation of IMCI because it aligns with their priorities

A2 NIHR HS&DR funding

A3 Those at risk of PUs will seek preventative guidance

A4 Those with previous/existing PU or HCP will seek escalation guidance or direction to NHS services

A5 Some will need signposting to NHS care

A6 Some will be confident to undertake

A7 Some will need help

Rationale: why one stepping stone leads to the next

R1 Most direct route to populations likely to benefit from intervention

R2 Involving key stakeholders in all aspects of development and evaluation will foster ongoing support for longer-term implementation

R3 PUP1 findings suggest that real patient stories (IMCI1) will engage users to consider own risk and to seek more detailed PU prevention skills

R4 Full IMCI informed by international PU prevention evidence and findings of PUP1 about how this can be enacted in a real world context

R5 If direct to area of intervention of most relevance to individual will find more useful and more likely to engage

R6 Facilitation of self management plans

Indicator: Things you can measure to show progress

I1 Design and pre-testing to confirm content, format and usability testing of intervention components

I2 Field test auto data capture of access information. Feedback on components

I3 Field Test Semi-structured interviews with users re experience of accessing and using the intervention

I4 Field Test Usability survey using the validated Health Information Technology Usability Evaluation Scale (Health-ITUES)

I5 Potential measurement of knowledge in users

I6 Potential measurement: number of users developing a safe routine plan, escalation plan, communication framework

I7 Measurement of activation

Abbreviations

SU: Service User; HCP: Healthcare Professional; PU: Pressure Ulcer; SIU: Spinal Injury Unit; LTNC: Long-term Neurological Condition; PA: Personal Assistant; TVN: Tissue Viability Nurse; IMCI: interactive multi-component intervention; Safe Routine: PU prevention activity developed around the individuals risk factors that facilitates communication about risk management

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.

Funding

This study/project is funded by the NIHR HS&DR: NIHR134029 - 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. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Declaration of competing interest

No conflict of interest have been declared by the authors.

Acknowledgements

We would like to acknowledge and give thanks to, Claire Roberts, Marcus Firth, Anne Firth, Deborah Whitaker, Alan Pickersgill, all participants, PURSUN members (past and present), the steering committee and third sector and community groups who supported the research.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jtv.2024.08.007.

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://tvscn.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 Muscoskel 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, Tanya 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 participtory 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/xgwlj0gn/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] Plsek 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.