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Synopsis

Pressure Ulcer Prevention at Home for People with Long-term Neurological Conditions, Carers and Personal Assistants: Synopsis – a Participatory, Qualitative study (PUP@Home1)

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Abstract

Background: Many people with long-term neurological conditions (e.g. multiple sclerosis, spina bifida) live independently and manage complex health needs, including mobility and sensory limitations which mean they have a high risk of pressure ulcer development. Despite their high risk, appropriate pressure ulcer prevention support and resources are often lacking.

Aims: To develop a Theory of Change pathway, which will underpin future development of a multicomponent intervention package supporting pressure ulcer risk identification and management, in partnership with people with long-term neurological conditions who self-manage care and live at home, their informal carers and personal assistants.

Methods: We used a partnership approach based in the participatory research paradigm, with extensive input from those whose lives are the focus of the research. The study comprised four interlinked work packages:

- |Work package 1 – Development of two co-operative inquiry groups
- |Work package 2 – Semistructured interviews and/or participation via a smartphone app
- |Work package 3 – Professional and strategic stakeholder engagement
- |Work package 4 – Systems mapping and Theory of Change pathway development

Iterative, qualitative data analysis was undertaken with emerging findings from each work package informing subsequent elements of the study.

Findings: Overall, 74 participants contributed across the 4 work packages. This incorporated 31 service users, 8 carers, 9 personal assistants and 26 professional stakeholders. The findings indicate the complexities of pressure ulcer prevention for this population, who are often fulfilling multiple roles in society (i.e. in their families, communities, work) alongside onerous self-care routines. Systemic and professional barriers were found to hamper people's ability

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to self-care, support others and seek help. Areas of learning were highlighted around developing safe routines, third sector and peer support, learning about pressure ulcer prevention, navigating complex systems, adapting and reacting to change, perceptions of risk, risk negotiation and the role of non-clinical carers. By collaboratively reflecting on these findings with key stakeholders (service users, carers, personal assistants, professional/strategic partners), we were able to identify points in the system amenable to change. This underpinned the development of a Theory of Change for a multicomponent intervention incorporating awareness raising, routine guidance, escalation guidance and communication components (supported by preconditions, contextual requirements, long-term outcomes, impacts and explanatory rationale).

Limitations: We acknowledge that despite our best efforts (incorporating targeted National Health Service and third-sector recruitment), the ethnic diversity of our research was not as representative as we had intended. We have included work to address this lack of diversity in our next study, including dedicated community workshops to explore the cultural relevance and appropriateness of our proposed intervention.

Conclusions: The study highlights the significant impact and complexities of managing pressure ulcer prevention activities at home, for people with long-term neurological conditions, carers and personal assistants. By understanding these complexities from different perspectives, we were able to develop a systems map and Theory of Change pathway informing future intervention development and evaluation.

Future work: Funding has been awarded for Pressure Ulcer Prevention at Home 2 (PUP@home2): Self-management intervention development and user testing for people with long-term neurological conditions (NIHR163165) to support pressure ulcer prevention and self-care, based on our learning from this study.

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A plain language summary of this synopsis is available on the NIHR Journals Library Website https://doi.org/10.3310/GJSC0721.

Introduction

This study sought to understand how people with long-term neurological conditions (LTNCs), currently identify and self-manage pressure ulcer (PU) risk at home. The study includes the perspectives of people with LTNCs and the people who support them, including informal carers, personal assistants (PAs), healthcare professionals and third-sector partners, such as charity employees. In this synopsis, we briefly outline our participatory approach and methods, which are described in detail in the study protocol.[2] We go on to outline our findings and share a Theory of Change (ToC) pathway, which is being used to underpin intervention development during a second study (PUP@Home2).

This research was developed and delivered collaboratively by service users, carers, PAs, academics and healthcare professionals. Throughout this synopsis, we refer to university researchers (staff employed in a research role) and peer researchers (service users, carers and PAs) to differentiate between different roles within the study. However, we acknowledge that the boundaries between those roles are blurred, and that people bring multifaceted life and professional experiences to research.

Background

Pressure ulcers

Pressure ulcers are areas of damage to skin and underlying tissue as a result of pressure, shear and friction to the skin. They are classified according to their severity ranging from Category 1: non-blanchable erythema to Category 4: severe cavity wounds exposing fat, muscle and bone.[3] UK prevalence data identifies 7–14% of hospital patients[4,5] and 0.51/1000 to 0.71/1000 of the community population[6,7] as having PUs. Primary risk factors for PU development are immobility, poor skin status and poor circulation.[8]

Our previous research and patient and public involvement (PPI) identified that PUs can be painful[8] and have a major impact on quality of life, affecting people emotionally, physically and socially.[9] Severe PUs can lead to months or years of treatment, including long periods of bed rest; frequent home or clinic visits; hospital admission for surgery or infection and loss of employment and education.[10,11] If untreated, severe PUs can be fatal. PUs costs are estimated at 4% of the NHS budget[12] and a mean 1-year community patient cost of £1400 for Category 1 and > £8500 for Category 4 PUs.[13]

Long-term neurological conditions

Long-term neurological conditions include, but are not limited to, multiple sclerosis (MS), spina bifida (SB) and spinal cord injury (SCI). The estimated spend across all LTNCs is £3.5% of NHS (£3.3B, 2012–3) and 14% of social care budgets.[14] Improved life expectancy; changes to health and social care structures; societal changes in attitudes towards living with disability; and personalised care funding have led to increasing numbers of people living independently while managing complex conditions.[14] People with LTNCs often self-manage their own care at home, with or without support from informal carers or PAs.

Long-term neurological conditions often affect people's mobility, which leads to increased PU risk. In addition, lack of sensory perception may reduce people's ability to feel and react to skin pain and changes to soft tissues, further increasing the risk of PU development.[15] Some people with LTNCs may also experience challenges, such as fatigue, difficulty concentrating and other cognitive impairments, which can affect their ability to manage PU risk and communicate when issues arise. While limited data are available regarding PU prevalence in people with LTNCs, a systematic review and meta-analysis estimated a high overall pooled prevalence of 32.36% [95% confidence interval (CI) 28.21 to 36.51] in people with SCI.[16] It is likely that PU prevalence in other LTNCs aligns closer to SCI populations than general adult populations.

As part of routine prevention practice, hospital and community nurses commonly use PU risk assessment instruments to identify those at risk. It is recommended that these assessments be undertaken in partnership with service users, to encourage shared decision-making.[17] Despite this, information is not always shared with service users or carers, they are not always encouraged to monitor or report PU warning signs and can be blamed for PU development.[9,18] Service users and their carers are often the only constant factor in a complex journey between health/social care professionals and settings.[19] They are uniquely positioned to monitor and manage their own risk, yet current service provision can hamper this.

Pressure ulcer prevention for people with long-term neurological conditions

Our PPI and other studies highlight the shortfalls and challenges of supporting people in the community, including, inconsistent professional support for people with LTNCs, missed opportunities and delays in care provision and communication difficulties between patient and healthcare professionals and services about PU risk and prevention.[9,14,18,20–22] While PU prevention has received a lot of attention from a clinical, secondary care perspective, there is limited evidence about if/how people with LTNCs self-manage their risk at home. Our study addresses an evidence gap regarding interventions which may help these high-risk individuals. In addition, there is limited knowledge about the role of informal carers and PAs. The idea for this research topic came directly from service users and carers,[22,23] who emphasised the need to go beyond patient education models and consider PU prevention from a broader systems perspective.

Aims and objectives

Aim

To develop a ToC pathway to facilitate the development of a multicomponent intervention package supporting PU risk identification and risk management, in partnership with people with LTNC who self-manage care and live at home, their informal carers and PAs.

Objectives

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

Methods

Participatory approach

This study is based in the participatory research paradigm. Participatory research aims for equal partnership between those conducting the research and those whose lives are the focus of the research, with stakeholders involved *with* (not just participating *in*) every aspect of a study.[24] This recognises participation as a right.[25] Participatory research is characterised by commitment to collaboration; collective project ownership; empowerment; critical reflexivity; valuing different types of knowledge (including experiential knowledge) and democratic processes.[26]

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Population

We aimed to explore the different perspectives and experiences of individual with LTNCs and the people who support them. Based on previous work we identified the following groups:

1. **Service users**: Adults with LTNCs which impact mobility, who self-manage care and live at home.
2. **Informal carers**: Defined by the NHS as someone who provides support for a family member/friend who would not otherwise be able to live independently.[27] Informal care is usually unpaid, although state benefits may support living costs.
3. **PAs:** Some individuals with LTNCs employ PAs. Their role is determined by the needs/wishes of that individual (e.g. personal care, domestic support, travel, leisure/social activities, or workplace support). PAs can be employed and paid through a number of mechanisms but are most often employed directly by the individual being supported.
4. **Professional and strategic stakeholders**: Representatives from services or organisations who provide support related to LTNCs and/or PU prevention.

Study structure

The study comprises four interlinked work packages (WPs) outlined in *Figure 1*:

WP1 – Co-operative inquiry
WP2 – Interviews and mobile ethnography
WP3 – Professional and strategic stakeholder engagement
WP4 – Systems mapping and ToC development.

We utilised an iterative design with emerging findings from each WP informing subsequent elements of the study. Each WP is described in more detail below. A collaborative evaluation of our participatory processes ran throughout all WPs and continues past the study end date.

Sampling and recruitment

We began the study with a period of outreach, identifying potential participants and partner organisations for all WPs. The sampling strategy sought to gain a range of experiences including diversity of LTNCs, previous experience of PUs, role (i.e. service users, carer, PA), age, gender, socioeconomic status and ethnicity. Emerging findings from each WP informed the sampling of the next. An overview of the recruitment target for each WP is provided in *Table 1*.

Recruitment was undertaken via charities; user/carer led groups; PA brokering organisations; existing research team contacts; professional networks; social media and snowballing. We also attempted to undertake recruitment via two NHS sites, this was unsuccessful.

Approximately 70, third-sector organisations were contacted, including, large charities, independent living centres, PA brokerage organisations, disability sports clubs and campaign/advocacy groups.

Out-of-pocket expenses and financial incentives were offered to all service user, carer and PA participants. People who took part in WP2 were offered a £20 shopping voucher after completion of their interview and/or app tasks. Co-operative inquiry group (CIG) members were offered payments via BACs for each research activity they took part in. Different rates were offered for different activities. CIG rates reflected the time and level of skill involved in different tasks and were in line with PPI payments across the host institute. Professional participants who contributed during work time were offered out-of-pocket expenses. Professionals who contributed during their own time were offered payments at the same rate as CIG members.

Data collection and analysis

Work package 1: co-operative inquiry group forming

Co-operative inquiry is a person-centred, participatory process where people research a topic through the lens of their own experience.[28] We established two parallel CIGs: one with people who have LTNCs and informal carers (N = 16) and a second with PAs (N = 3). Each group also included university researchers. Groups followed an adapted version of Heron's partial form co-operative inquiry methodology.[28]

1. **Group forming**: Creating a safe space and developing a partnership agreement and shared values (see *Appendix 1*).
2. **Self and group reflection**: CIG members shared personal experiences via an adapted version of the 'Rivers of Life' method[29] (see *Report Supplementary Material 1*) and facilitated small group discussion, identifying common themes together.
3. **Preparation for WP2 –** CIG members co-designed the WP2 interview topic guide and smartphone app tasks (see WP2 description and *Report Supplementary Material 2*) and agreed a sampling strategy. CIG members volunteered to undertake interviews and user-test/monitor the app.
4. **Continued immersion** – CIGs continued to meet regularly throughout the study, moving between participant and peer researcher roles at different points.

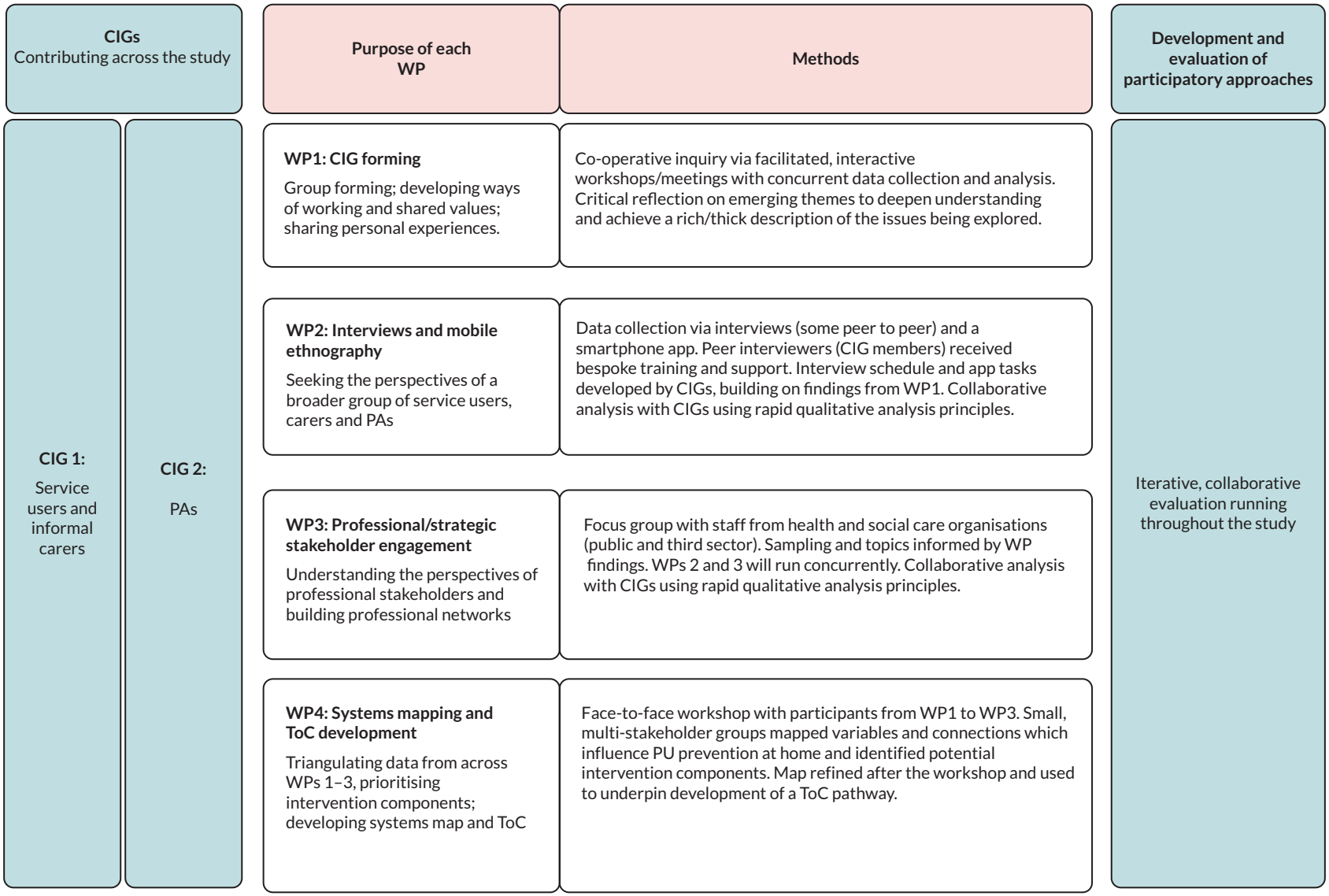

FIGURE 1 Study overview. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

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TABLE 1 Recruitment targets

WP	Recruitment target
CIGs	Group 1. Approximately 8 people living with a LTNCs and informal carers Group 2. Approximately 8 PAs
Interviews and mobile ethnography	24–30 people living with a LTNCs, informal carers and PAs
Professional/strategic stakeholder engagement	12–14 health/social care professionals and strategic partners
Systems mapping and ToC development	Participants from WP1 and WP3 plus new participants identified based on emerging findings

Work package 2: interviews and mobile ethnography

Work package 2 participants provided data via a semi-structured interview, a smartphone app or both. Interviews were conducted by CIG members (both peer and university researchers) either face-to-face or via a video call. Smartphone app participants were sent tasks across a 2 to 3 week period via an app called Field Notes (see *Report Supplementary Material 2*). Where people chose to participate in both the app and interview, they were asked to complete the app tasks first and entries were explored further in the subsequent interview.

Work package 3: professional/strategic stakeholder engagement

Face-to-face focus groups[30] aimed to both understand the perspectives of professionals who support community PU prevention and build a network of partners to aid dissemination and implement future interventions. Topic guides and sampling were informed by emerging findings.

Work package 4: systems mapping and Theory of Change pathway development

Systems mapping is a collaborative technique used to understand and present complex health problems and capacities within a system of contributory factors.[31,32] Participants joined a full-day, face-to-face workshop. Emerging study findings were presented as a composite case study, which was developed by CIG members, and presented by an actor. This aimed to bring data to life in an accessible way, while maintaining the anonymity of participants. A university researcher then presented a draft systems map, based on the factors mentioned in the case study. Participants were split into small, facilitated, mixed stakeholder groups, to review and add to the draft map. They were asked to build this into a larger map, to capture factors affecting PU prevention more broadly from their different perspectives and roles. Then they were asked to identify points in the system which would benefit from intervention(s) and discuss what those interventions might look like.

After the workshop, a university researcher led the refinement of the map, combining comments from across the small groups. A second university researcher led the refinement of intervention components and developed a draft ToC pathway, describing how contextual factors are likely to influence desired changes.[33,34] The map and ToC were refined via multiple rounds of feedback from workshop participants and wider CIG members.

Analysis

Analysis across all WPs was informed by the principles of rapid qualitative research[35] in combination with collaborative framework analysis.[36,37] During early CIG meetings, group members identified and recorded common themes emerging from discussions. Those themes were used to create a Rapid Assessment Procedure (RAP) sheet. RAP sheets are a tool used to summarise and share emerging findings. They provide a template for researcher notes, building themes 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. *Appendix 2* provides a detailed breakdown of data collection and analysis across each WP (see *Appendix 2*, *Table 3*).

Results summary

Overall, 74 participants contributed across the 4 WPs. This included 31 service users, 8 carers, 9 PAs and 26 professional/strategic stakeholders. The participants were diverse in terms of the LTNCs they had experience of, their age (ranging from 25 to 29 bracket to the over 75 bracket) and their socioeconomic status. Most of the participants identified as White. *Appendix 3* outlines participant characteristics and how they contributed to the study (see *Appendix 3*, *Tables 4* and *5*) and representation is addressed in *Equality, diversity and inclusion*.

We identified eight themes across all WPs: 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 described in the narrative summary below.

Learning

Learning needs

Throughout the study, many conversations explored how people learn about PUs and health more broadly, including where people felt they had unmet learning needs. Service users described varying PU prevention needs. Many service users said they had never been given, or did not remember, any information about PU risk, with some stating they were not aware of their risk until involvement in the study. Those people identified a need for awareness raising activities. As described in *Safe routines*, other service users were acutely aware of their risk and had already integrated PU prevention into their lives. That group wanted more information and support regarding when and how to seek help should they spot signs of pressure damage (see also *Navigating complex systems*).

> *I've never been given any advice on pressure sores. I've not really been told pressure ulcers were an issue I might face, or given information on them. I realised reading through some Web based literature, having signed up for this study, that my sore dry, cracked, discoloured elbows were just that, I have mentioned them to the GP before, they just told me to keep moisturising them… I believe I have grade 1 pressure sores on my elbows.*
>
> *Service user, 016WP2, Smartphone App*

Communication

People who had received PU prevention support reflected on the timing and delivery of that information. For example, many people with spinal injuries described a focus on skin care during their early rehabilitation. However, people talked about the intensity of that time and how difficult it was 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, 001WP2, Smartphone App*

Many people talked about the importance of health information being staggered or repeated over time and of health professionals tailoring information to the individual in front of them. Factors such as fatigue, mental and physical health, literacy, stress, and cognitive impairments all impacted people's ability to seek out, process and act on information on a given day. At times, carers and PAs played a role in finding or interpreting health information. There was a feeling that some professionals saw the provision of PU information as a 'box ticking exercise' rather than part of true shared care and decision-making (see also *Risk negotiation*). At times, people reported inconsistent PU advice from the different professionals they came into contact with.

In addition, many existing PU prevention resources (e.g. leaflets) focus on understanding patient level, clinical risk factors. Participants wanted more consideration of wider contextual factors (see also *Risk negotiation*) and how to adapt PU prevention strategies when their condition or lives change (see also *Adapting and reacting to change*).

People did share some positive examples of PU prevention education. People who had come into contact with tissue viability nurses spoke positively about their input. However, TVNs were rarely involved in primary prevention and were only called upon for the most serious PUs. Some service users suggested that TVNs should play more of a role in PU risk assessment and education, particularly for people with complex risk profiles. Many people also talked positively about spinal injuries units (SIUs), describing them as a source of ongoing support and information. However, SIU service provision varies and some people with SCI are not under their care. In addition, that service is not replicated across other LTNCs.

Education for carers and personal assistants

Personal assistants and carers reported very limited opportunities to learn about PU prevention. They described learning about PUs over time, through sporadic detail given by health professionals or via the person they support. Many PAs did not see PU prevention as part of their role and were unsure of what action to take if they became aware of skin damage. None of the PAs involved in this study had accessed formal PU prevention training prior to the study and there was notable variation in the training and support that PAs received more generally. Some PAs were frustrated by the lack of paid time to attend training. Although some had accessed training grants, that funding only covered the cost the training, not their time to attend.

We found that the burden of PA training often falls to the individual or family they support. Some service users talked about having multiple PAs/carers, sometimes with

a high staff turnover and recruitment challenges. They reported that the process of finding and training PAs was often stressful, with service users sometimes struggling to ensure their needs were adequately understood.

> *[W]hen I get new carers, I have to be verbal in terms of my instruction because I can't show them. The number of times that I wish I could stand up and say, 'What I really need is this' and I could show them, I can't even begin to count. So I think what I was trying to say is that if you're constantly having to train new people, I don't get much respite either.*
>
> *Service user 015WP2, Interview*

Safe routines

Service users described complex self-care routines, which often involved balancing multiple needs and risks, sometimes across multiple conditions. For many, PU prevention was just one small part of a very complicated self-management picture. Self-care was understood in broad terms, with people highlighting the importance of mental health and emotional well-being alongside physical care. Many participants described developing problem-solving skills to support their self-care or the care of others. For example, many service users developed successful PU prevention routines and shared strategies which help them to live PU free. Strategies included, using a mirror or photographs to view areas they would not otherwise be able to access (e.g. sacrum and buttocks); setting an alarm on a smartwatch to prompt position changes; regular application of creams; written care plans for hospital admissions; specialist clothing and seeking help (e.g. asking carers/PAs to do regular skin checks).

> *Buying jeans that are made for wheelchair users, so they have got the soft seams, they haven't got the double French seams, they haven't got pockets, they haven't got rivets, they come up right to your waist.*
>
> *Informal carer, 027WP2, Interview*

> *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, 005WP2, Interview*

Some systems mapping participants conceptualised this kind of activity as a 'safe routine' that is a set of flexible PU prevention activities developed around the specific needs of an individual, taking into consideration both their clinical risk factors (e.g. mobility, skin status and sensory perception) and the wider context of their daily lives.

Third sector and peer support

The third sector was widely cited as providing valuable resources and support for people with LTNCs, their carers and PAs. For example, 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 (e.g. within SIUs), social media forums and support from friends.

Service users, carers and PAs cited several reasons for seeking support from outside of the NHS:

1. **Gaps and complexities within the NHS** – people did not always know which part of the NHS to access for support with specific aspects of a condition (see also *Navigating complex systems*). Condition-specific charities were seen as an important 'one stop shop'.
2. **Timely access** – people described long waits to access NHS support. In contrast, online resources provide real-time support, including out of hours.
3. **Desire to minimise NHS burden** – some service users described feeling a responsibility to take charge of their own care. There was a general perception that the NHS is overstretched, with several service users, carers and PAs expressing empathy with professionals working in difficult circumstances.
4. **Valuing lived experience** – people described valuing and trusting the perspective of others who have lived through similar experiences. Peer groups were viewed as a safe space for both emotional support and practical advice. This is something that we witnessed first-hand during our study CIG meetings.

> *Speaking with carers of people with many different conditions is very beneficial. Social media, closed groups on Facebook, is often a good platform for asking safe and anonymous questions.*
>
> *PA, 013WP2, Smartphone App*

> *We would respond to other disabled people.*
>
> *Service user, 015WP2, Interview*

> *My personal opinion is that I need to be responsible for my own care especially now with the pressures on the NHS services.*
>
> *Service user, 004WP2, Smartphone App*

Limitations

Although many participants utilised and highly valued third-sector support, there was a sense that organisations were increasingly picking up care that would have previously been provided by the public sector. Although third-sector resources such as online information and

phonelines were helpful, people still reported a lack of face-to-face, clinical support in the home. Similarly, people recognised the limitations of peer support. Some service users were mindful that advice given by peers may be based on just one person's experiences. Therefore, advice may not be accurate or appropriate for other people's circumstances. Some participants identified a gap in resources which bring together peer experiences with evidence-based information.

Navigating complex systems

Mental load

Service users described the huge complexities of managing their care, requiring negotiation of multiple, complex systems and processes, including NHS and social care services; finance (e.g. benefits, equipment grants, training grants); recruitment, employment and training of PAs; and third and private sector input. Many participants talked about the high mental load and stress associated with self-management, with some reporting a negative impact on mental health.

> *I think I spend a large proportion of my time either managing my care situation, or managing the medical situation that I'm in, so dealing with appointments, dealing with scheduling appointments, dealing with getting hold of doctors, chasing things up when things don't happen, all that sort of thing. That I think I consider these days to be my full-time job.*
>
> *Service user, 015WP2, Interview*

Many LTNCs require cross medical specialty services and do not have a single dedicated clinic. Service users described attending multiple appointments with different specialties, with limited communication between teams. PUs are also a cross specialty condition with a variable patient pathway. Service users, carers and PAs all described having to fight to get the support they needed. Others said they had little to no contact with clinical services, either by choice or because they had fallen through the gaps.

Advocacy

Many service users reflected on the challenges of self-advocacy, particularly when feeling unwell, fatigued or low.

> *There's only so much you can physically you can do yourself, there's only so much bandwidth that you're bringing and if you're in pain, which I am sometimes, that becomes even more difficult because the pain is your focus.*
>
> *Service user, 015WP2, Interview*

Several service users reported that their previous experiences of the NHS had an impact on their ability and willingness to self-advocate. For example, some participants described slowly building up knowledge of their local systems and what to say to be taken seriously by professionals. However, other people did not feel listened to by professionals or were blamed for PU development, causing them to disengage. Carers and PAs shared many examples of them acting as advocates, describing advocacy as a vital but challenging aspect of their role. Carers and PAs also talked about their own health and emotional well-being, which affects their capacity to be an effective advocate. The complexity of NHS systems makes PU care escalation extremely difficult. Given the potential seriousness of PUs, people felt it took too long to get 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, 001WP2, Interview*

Siloed NHS

Several service users suggested that primary care staff were well placed to help them navigate local NHS services. However, some professional participants felt that primary care staff did not currently have the resources or the knowledge to do that. Many of the frustrations felt by service users, carers and PAs were shared by the professional participants. Professionals acknowledged the disconnect between different services and roles. Some professionals reflected on their own experience as family carers and the challenges of getting appropriate, timely support, despite their enhanced knowledge of the NHS.

> *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?*
>
> *Professional, 005PR, Focus Group*

Private sector

People told us that the private sector plays a significant role in PU prevention and treatment, and the care of people with LTNCs more broadly. Several service users, carers and PAs described utilising the private sector to access products that were not available via the NHS. Private services also allowed people to circumnavigate

NHS equipment assessments, which were often found to be slow and repetitive. People also described tensions between service users and NHS professionals regarding the most suitable equipment.

> *And you can stand there with black and white and you can have the pressure mapping evidence and say, 'No, this is better than anything else you're sitting on', and it's like, 'Well no, because I read the reviews on Amazon about this lovely cushion, and it's supposed to be a high pressure relief cushion'. It's like, 'No, honestly, we trialled it ourselves and it's rubbish, and you should not be sitting on it'.*
>
> *Professional, 002PR, Focus Group*

Those tensions led to some service users looking outside of the NHS, with some telling us they valued expertise within the private sector. We found examples of service users seeking health advice direct from product manufacturers when they did not feel supported by the NHS.

> *I use a company called [name of company] …. I find that their knowledge is more tailored around those with a spinal cord injury. We heal differently. The advice and products used by the NHS don't suit me or my healing. [Name of product] speeds up healing time significantly… [Name of company] are current and up to date with their research. They specialise in spinal cord injury skin and how it heals.*
>
> *Service user, 001WP2, Smartphone App*

However, some professional participants voiced concerns about the variability of advice given by private companies and the lack of an evidence base for some products. Participants across all groups shared concerns that the private sector role may be exacerbating health inequalities, as people who can pay may get a better or faster service. In addition, although equipment grants are available through the third sector, some people did not know about them, and others described them as yet another bureaucratic process to navigate.

Adapting and reacting to change

'Spinning plates'

In addition to the complexities of managing care, service users talked about navigating the normal highs and lows of daily life. For example, they are carers, parents, and friends; they work, volunteer and play active roles within their families and communities. Participants described feeling like they were 'spinning plates' while balancing their personal commitments with their complex care needs. People described those contextual factors as having a huge impact on their PU risk and their self-care regimes more broadly.

Danger points

People's lives and clinical risk factors (e.g. mobility) change over time. People reported feeling unsure of what to do when their safe routines no longer worked or were no longer practical. People described 'danger points' in their lives when their risks changed or where self-care became more challenging or less of a priority. For example:

- Life events, for example bereavement, changing jobs, moving house, becoming a parent.
- Temporary change, for example a holiday, changes in weather.
- Care transitions, for example moving between services or a change in PA.
- Acute illness or injury.
- Changes to mood, for example becoming depressed and feeling less motivated or able to self-care.
- Ageing.
- Deterioration or fluctuation of existing LTNC.
- Developing additional long-term conditions.

> *We love going on holiday but there are so many additional problems because you are doing that and it's trying to mitigate all that isn't it.*
>
> *Carer, 006CIG, CIG Meeting*

Flexibility

Some professional stakeholders were frustrated by the lack of flexibility within their roles. In contrast, PAs talked about their ability to adapt to an individual's changing needs and wishes. Although the lack of formal role boundaries can cause challenges (see also *Supporting roles*), some PAs described this flexibility as a positive aspect of the work.

Perceptions of risk

We found that that people's perception of their PU risk also changed over time and some people found it hard to engage in conversations about future risks. For example, some service users found it difficult to think about how they may cope if their condition deteriorated or was impacted by ageing. Perceptions of PU risk also appear to be influenced by the attitudes of the health professionals that people come into contact with, particularly the extent to which skin care is prioritised during those discussions. Some professional participants suggested that cognitive impairments may also affect how people perceive their own risk.

Impact of having a pressure ulcer

Some service users said they had not appreciated the importance of PU prevention until they had experienced a PU. Many at risk skin sites are hidden from view and people may not feel early skin damage due to sensory perception issues. That led to some people not prioritising the care of those areas or fully appreciating the relevance of PU prevention advice prior to having a PU.

Service users reported becoming 'hypervigilant' after having a PU and making future PU prevention a priority. That change in mindset was partly due to the significant emotional impact that PUs had on service users and their families. Both service users and carers described feeling shame and guilt, feeling that PU development was a failing of their self-care or their care for a family member. That self-blame made it harder to seek professional help. At times, those feelings were reinforced by the attitudes and actions of healthcare professionals (see also *Risk negotiation*). Service users also discussed the major impact of PU treatment interventions, for example long periods of bedrest taking people away from work, education and family and, understandably, affecting people's mental well-being.

> *That is seven months of my life I'm never going to get back.*
>
> *Service user, 015WP2, Interview*

Encouraging vigilance

Participants reflected on how PU vigilance could be encouraged before a PU developed. Some people recalled being shown graphic images of serious ulcers, as a way of demonstrating the potential severity of PUs. Participants had mixed feelings about the use of PU images as part of PU awareness raising. Images were described as memorable and a potential motivator to take PU prevention seriously. However, others found images to be scary and counter-productive, causing disengagement with the topic. There was general agreement that images could be a helpful learning tool in terms of PU identification; however, they may be less helpful when framed as warnings or threats. Some participants suggested that peer stories were more appropriate for communicating the potential severity and impact of PUs.

Risk negotiation

Tensions

At times, service users and health professionals appear to have different perceptions of risk and be willing to accept different levels of PU risk, influencing their ability to share decisions. Service users clearly stated that they need flexible prevention strategies, which they can fit within their existing self-care routines and lives. We found a tension between that desire and the approach of some health professionals. At times, service users felt that health professionals were unwilling or unable to deviate from standard advice, even when that advice was not practical in the context of their life. When people failed to follow advice, they were sometimes labelled as 'non-compliant' or blamed if a PU developed or deteriorated.

> *It comes back to that patient concordance and about whether they will follow those instructions or not, and then it's a case of if not, then the question of why they won't, I don't think gets fully investigated. We often get them in the hospital, and we have these meetings and discuss them, and its patients where they're deemed to have capacity but they're choosing to make what we would deem as being unwise decisions.*
>
> *Professional, 009PR, Focus Group*

At times, tensions between service users and professionals led to people with LTNCs disengaging 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, 004WP2, Smartphone App*

Power

It was acknowledged that conversations about risk can be complex and challenging, requiring strong communication skills on all sides. Some service users described feeling a power imbalance between themselves and professionals, which makes communication more challenging. However, some service users, carers and PAs did feel that they had developed skills which meant they were able to negotiate on a more even footing. For example, learning how to articulate their needs, including 'trigger' words which are taken seriously by professionals.

Organisational constraints

Some professionals described constraints within their role or organisation which impact their ability or willingness to negotiate. For example, limited time with individuals, being unsure what else they can offer, task-oriented appointments and blame culture. Some professionals feared litigation if they deviated from what is considered

best practice. More experienced, senior staff appeared to be more willing to accept higher risk levels.

Supporting roles

Informal carers

Some service users told us they did not involve family members in their care, either because it was not possible or out of choice. Some said they felt guilty when prioritising their needs over their family. Others expressed a desire to keep family separate from the more personal or medical aspects of their care.

> *I try to completely separate the care from their [family] involvement. I've had them help with an odd turn or helping me pull a pair of trousers on when I've only had one carer there, and it's been assisting. But any of the clinical stuff, dressings, bowel management, catheter stuff, occasionally I'll get them to help me empty the catheter if I can't get to it, but most of the other stuff I try and keep them away from.*
>
> *Service user, 017WP2, Interview*

However, many people indicated that their families did provide vital support and advocacy (see also *Navigating complex systems*) and we heard examples of informal carers playing an important role in PU prevention, for example, helping people to turn, checking skin or escalating care. LTNCs, PU prevention activities, PU treatment, self-care regimes and caring for others were all found to have an impact on family dynamics. Many people talked positively about the strong bonds, trust and resilience which develop within families, the continuity of care that families provide and the two-way nature of support.

> *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, 016WP2, Interview*

> *When you're in that kind of a relationship, you love them and want to do what's best for them.*
>
> *Carer, 006CIG, CIG Meeting*

In contrast, some people discussed the challenges they faced in caring roles, for example expressing a desire to maintain their original family relationships (e.g. husband and wife) rather than being defined as a carer.

> *Then [name of PA] arrived and took us to the Safari park, one of our favourite places. xx pushed my wife around so I could be husband and not carer.*
>
> *Carer, 006WP2, Smartphone App*

Others spoke of feeling overwhelmed or out of their depth. Several carers described a negative impact 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, 006CIG, CIG Meeting*

Carers 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.

> *I should have realised your shoes were too tight and shouldn't get to the point that you have a PU, I should have a noticed when it was a reddened area or whatever and you do feel like – oh… I let this happen.*
>
> *Carer, 006CIG, CIG Meeting*

Personal assistants

Many of our conversations explored the relationships between PAs and the people they support, and the impact those dynamics have on the type of care they provide. PAs talked about the rewarding nature of their work and service users talked about the important role that PAs play in maintaining independence. Some PAs described feeling like part of the families they support and reflected on the positive and negative implications of that dynamic. For example, some PAs build close, trusting relationships with their clients, meaning they see aspects of people's lives which other professionals do not.

At times those close bonds led to personal and professional boundaries becoming blurred and some PAs said they found it hard to say no when asked to do something they did not feel was appropriate. PAs described working more hours than they were contracted to do, or agreeing to tasks that they did not think were part of their role, to avoid letting clients down. Some described an intense feeling of responsibility. In extreme cases, people shared examples of putting their own safety at risk to help clients. The wider context of PA employment is complex and has

an impact on the PA role. In addition to a gap in PU prevention resources, PAs also identified a need for more general employment support and guidance for both PAs and the people they care for, for example, around role negotiation, boundary setting and challenging conversations. Most PAs did not see PU prevention as part of their role; however, many recognised that they may be well placed to spot skin damage or to notice and respond to changes in risk.

Systems mapping

The themes above are illustrated in our systems map (*Figure 2*), which visually demonstrates the complex nature of PU prevention activity. Maps with larger text, which focus on different clusters of information, are available in *Appendix 4*, *Figures 4*–*8*.

During WP4, we identified potential intervention components, which are shown on the map. We propose an interactive, multicomponent intervention, including resources for people with LTNCs, informal carers, PAs and healthcare professionals. It will be an online intervention, with paper copies available. Our results highlight the need for an intervention that is clear, accessible, interactive and engaging; that brings together peer stories with evidence-based information and that is flexible enough to allow people to use in different ways, based on their individual needs. We anticipate the full intervention will comprise of four components:

1. Awareness raising materials which outline what a PU is, who is at risk and why PU prevention is important (including peer stories).
2. Support to develop personalised safe routines, which consider physical risk factors, wider factors within people's lives, and how to plan for and react to change.
3. Care escalation guidance covering when, who and how to seek help.
4. A framework to support risk communication and negotiation between service users, carers, PAs and professionals.

The proposed intervention and its intended pathway to impact are described in more detail in the ToC pathway (*Figure 3*).

Theory of Change

The ToC illustrates the causal pathway suggested by the research to achieve change and real-world impact.[33] Key 'stepping stones' in our pathway are shown as lilac boxes, which represent pre-conditions that need to be in place to achieve desired long-term outcomes (pink boxes), for example, person-centred care and eventual impacts (orange box) such as improved quality of life and reduced PU incidence. Our refined intervention components are integrated within the pathway as green lozenges (with detailed explanations of each component in the green box below) and are intended to facilitate movement from one stepping stone to the next. These are supported by assumptions and rationale to facilitate pathway progression. Assumptions are factors beyond the control of the intervention and potential barriers are illustrated as yellow circles (and further explained in yellow boxes below). Rationale indicates why one stepping stone leads to the next and are illustrated as pink circles (and further explained in peach boxes below). Finally, indicators or properties that can be evidenced to show progress are illustrated as blue circles (and further explained in blue boxes below). The ToC will be used to underpin intervention development in our next study, PUP@home2.

Discussion

Putting our findings into context

Self-care and self-management

Many people with LTNCs demonstrate significant resilience, problem solving and self-management skills, despite difficult circumstances. In recent years, people living with chronic conditions have been encouraged to take more responsibility for managing those conditions. Many of our participants expressed a willingness to do that but said systemic barriers made it more difficult. In addition, our work and wider literature on burden of treatment[38] suggest that people can become overwhelmed or burnt out by self-management or supporting others.

> *Health services face the challenge of growing populations with long-term and life-limiting conditions, they have responded to this by delegating to sick people and their networks…This is the new proactive work of patient-hood for which patients are increasingly accountable: founded on ideas about self-care, self-empowerment, and self-actualization, and on new technologies and treatment modalities which can be shifted from the clinic into the community. These place new demands on sick people, which they may experience as burdens of treatment.*[39]

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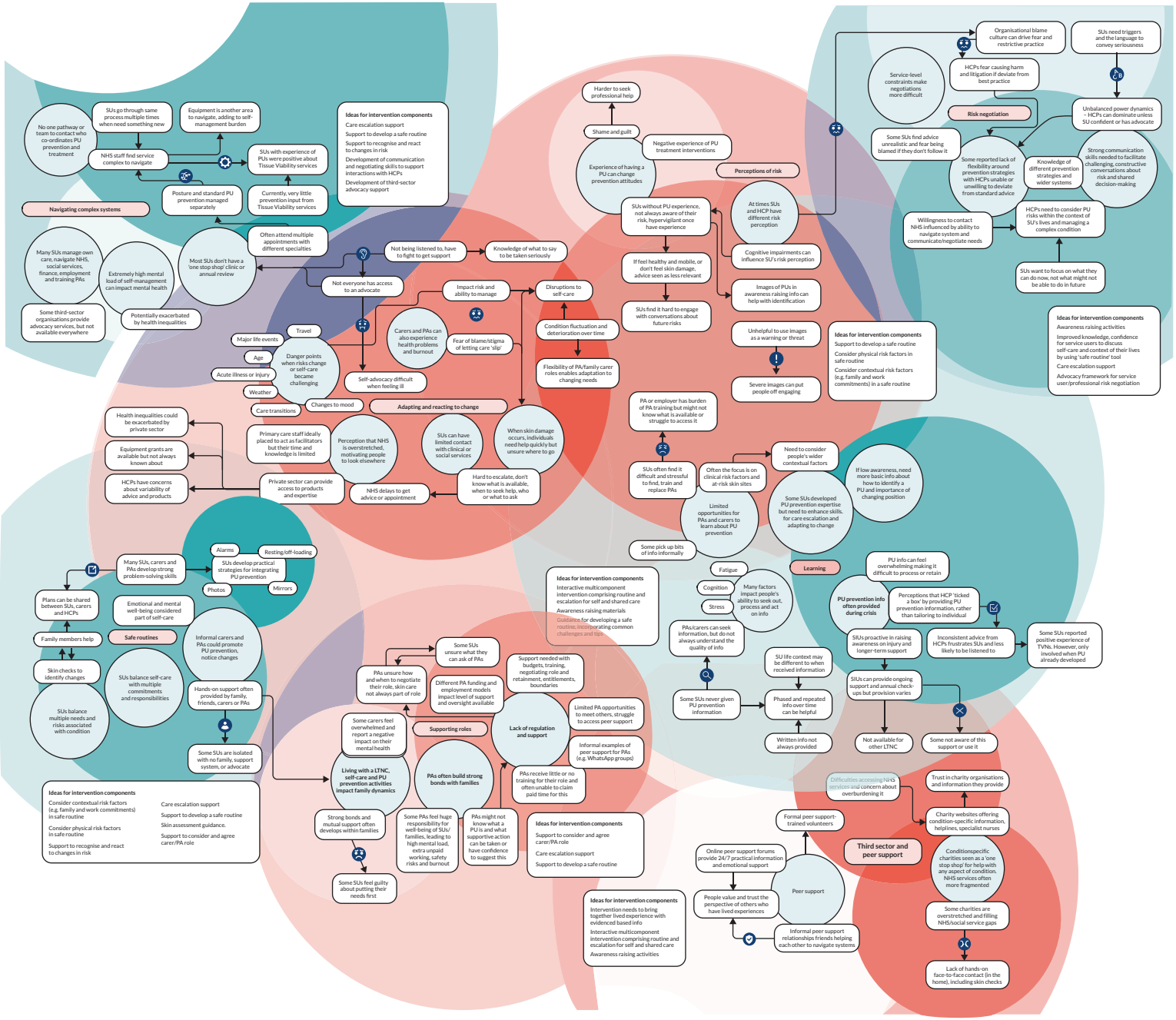

FIGURE 2 Systems map overview. SUs, service users. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

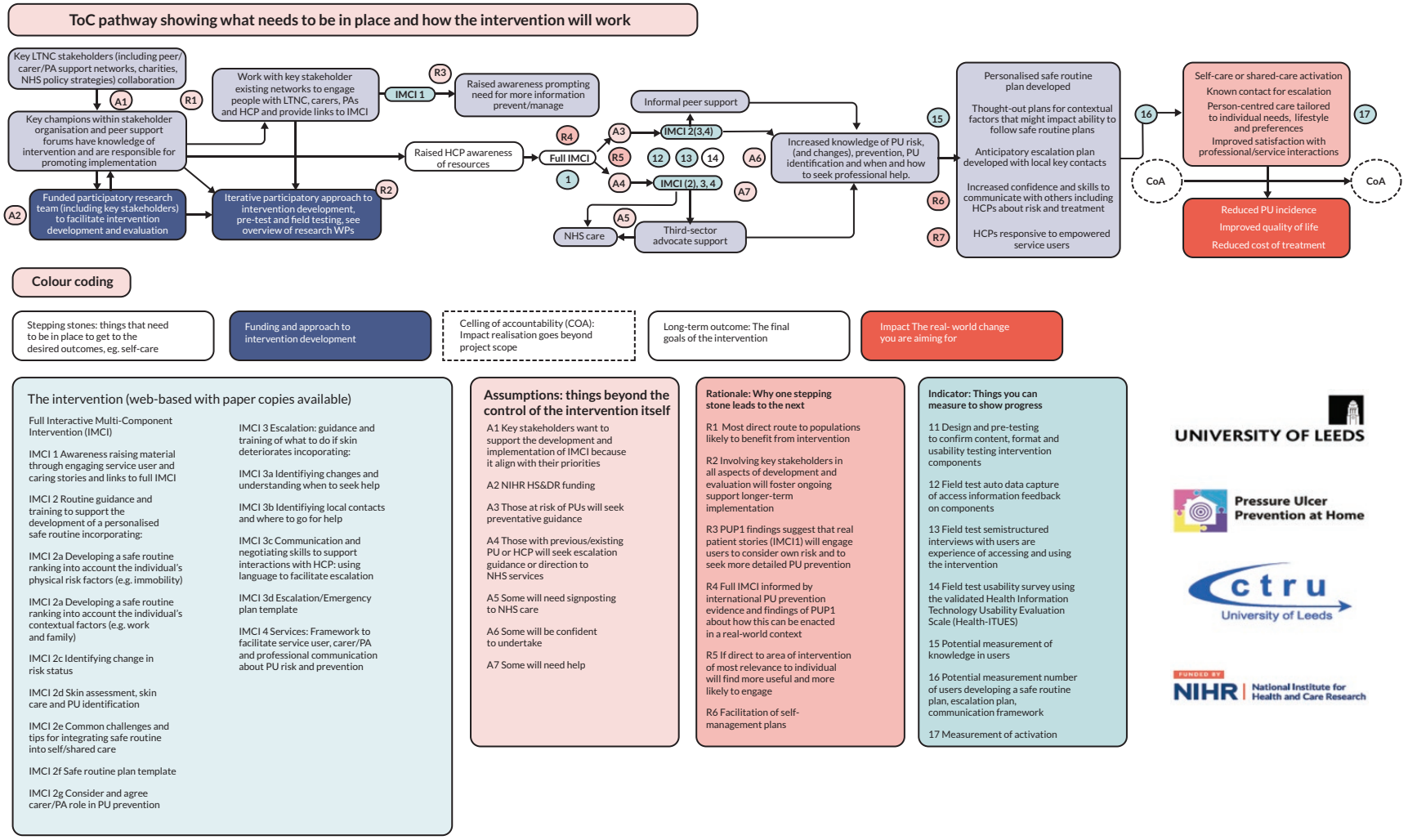

FIGURE 3 Theory of Change pathway. HCP, healthcare professional; IMCI, interactive multicomponent intervention; LTNC, long-term neurological condition. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

This synopsis should be referenced as follows: Muir D, McLarty L, Drinkwater J, Bennett C, Birks Y, Broadway-Parkinson A, *et al.* Pressure Ulcer Prevention at Home for People with Long-term Neurological Conditions, Carers and Personal Assistants: Synopsis – a Participatory, Qualitative study (PUP@Home1). *Health Soc Care Deliv Res* 2026;**14**(20). https://doi.org/10.3310/GJSC0721

The text above includes minor additions and formatting changes to the original text.

People find navigating services and escalating care particularly difficult. Increasing treatments, specialisation and technology have led to healthcare systems becoming increasingly fragmented and hard to negotiate.[40–43] That process can be particularly complicated for people with complex needs and comorbidities,[14,41,44] especially if they have a cross-speciality issue, such as a PU.[8,13] 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 with care and respect.[43]

Given the increasing self-management responsibility placed on service users, the ability to self-advocate is a vital yet undervalued skill. Advocates, such as family members and PAs, also play a vital role in accessing appropriate NHS support. However, some people do not have the support of an advocate and we recognise this as a potential sticking point within our future intervention. Some people may not be able to understand PU prevention information or escalate their care without support. Formal advocacy services do exist, for example, within the third sector; however, those services were rarely mentioned by participants in this study. One potential explanation for this is that individuals who require formal advocacy may also face barriers to research participation. Therefore, they are likely to be underserved by this and other research studies.[45] More work is needed to explore what kinds of advocacy exist for different LTNCs, enabling us to identify gaps and signpost support as part of our future intervention.

Risk perception and management

When people with LTNCs do access health services, they sometimes encounter challenging interactions with healthcare professionals. Conversations about risk can be particularly difficult. Our findings support other work identifying differences in the way service users and healthcare professionals perceive PU risk and its management.[20,21,46,47] Service users' perceptions of risk are influenced by their first-hand experience (or lack of) of having a PU, or knowledge shared by those who have.[19,21] The struggle of balancing PU prevention (i.e. pressure relief sometimes involving periods of bedrest) with an active and fulfilling life has also been emphasised.[21,46–48]

In keeping other research, service users in this study voiced frustration with some healthcare professionals' inflexibility around PU prevention.[38] Healthcare professionals described concerns about deviating from 'best practice' due to fears of blame and/or litigation if things went wrong. This echoes Coleman *et al.* who found that nurses reported concerns about getting 'things wrong' in PU prevention and subsequent risk aversion, particularly in those with less experience.[49] Work in other areas concurs; in an emergency department study, less experienced doctors were found to be more risk averse and have increased difficulty dealing with uncertainty, resulting in more risk-averse decision-making.[50] In the context of PU prevention, this could explain why some healthcare professionals are more inclined to stick rigidly to 'best practice' guidance and why service users are often willing to accept more risk. These differing perceptions of PU risk and prevention make conversations about risk difficult, yet findings from this study and others[21,47,51] suggest those conversations need to occur.

Epistemic injustice

Epistemic injustice is another phenomenon that can hamper honest, helpful conversations about PU risk. This occurs when a particular person or group are given less credibility and are therefore excluded, ignored, negatively stereotyped, or not believed.[52] In a healthcare context, this often presents as a knowledge hierarchy, where clinical training and expertise are valued more highly than lived experience.[53] Previous research suggests this is common within health conditions such as mental health[54] and chronic fatigue syndrome.[55] In a study investigating why some people develop severe PUs, Pinkney *et al.* found that service users' concerns were often ignored and that people were blamed when ulcers developed.[18] In our study, many service users, carers and PAs described a power imbalance between themselves and health/social care professionals, and people were labelled as 'non-compliant' when they did not follow professional advice, even when that advice failed to value their lived experience.

This issue is more complex than improving communication within clinical consultations. Healthcare systems are often hierarchical in nature, with policy and culture that make it harder for professionals to work in partnership with the people they support.[43] In addition, service users may not have access to support or resources which encourage them to make sense of, value and communicate their own expertise.

> *Epistemic justice is about allowing or enabling people to think about their own experiences in ways that value those experiences, and support theorising about lived experience…The approach also endorses the view that multiple perspectives might exist and appear contradictory, but might all be valid and together to represent a more complete picture.*[54]

Mooney suggests that participatory research is a valuable way of exploring and addressing epistemic injustice within health care, as it seeks to democratise knowledge and values multiple forms of expertise.[54] This is echoed by Hui,[45] who suggests that, if important voices are excluded from the creation of evidence, evidence-based practice will continue to underserve those groups. Our experiences further support those recommendations. However, we recognise that creating truly democratic research partnerships is challenging in practice. Please see *Reflections on the project* for discussion of both project level and wider systemic challenges.

Health inequalities

Underserved communities are more likely to experience epistemic injustice[45,56] and the prevalence and impact of health inequalities more broadly is well documented.[45,57–59] Evidence suggests that people living with disabilities are disproportionately affected by health inequalities and that unmet healthcare need is a key contributory factor.[38,60] This is supported by research in other fields, with multiple studies suggesting that people from marginalised groups face more barriers when attempting to navigate health and social care systems.[45,61–63] Our results add to that body of evidence, demonstrating that many people with LTNCs feel their needs have not been met or that they have had to fight to get support.

It is widely acknowledged that people from minority ethnic communities experience health inequalities[64] and structural racism within health and social care.[45,56] Within a PU prevention context, there is evidence that early skin damage is more likely to be missed when someone has a darker skin tone and that diverse skin tones are not adequately included in skin assessment resources.[65] In addition, we found some limited evidence that ethnicity and culture may impact PU prevention activities more broadly, for example, due to health beliefs, cultural expectations around caring for family members or language barriers. However, this data primarily came from professionals with experience of engaging with culturally diverse families, rather than from the families themselves. Therefore, we are cautious about drawing conclusions without further work (see also *Equality, diversity and inclusion*).

The influence of the private sector raises further concerns about socioeconomic disadvantage. The use of medical devices, such as specialist mattresses, cushions and dressings, is common within PU prevention and treatment and many devices are available without a prescription. However, some of those devices lack a strong evidence base and manufacturers are not required to provide evidence of effectiveness through clinical trials.[66] We acknowledge that some participants in this study had positive experience of the private sector. Direct purchases allow people to circumvent long, frustrating NHS assessment processes and provide people with more autonomy over the equipment they use. However, those positive aspects must be balanced with legitimate concerns regarding evidence gaps, inequality of access and the ethics of companies selling directly to potentially vulnerable service users.

Support in the home

Pressure ulcers are typically viewed as a nursing led, clinical issue. As such, many of our findings relate to the relationships between people with LTNCs and NHS professionals/services. However, many people access PU prevention support from outside the NHS, including the third sector and peers. Many service users highly valued and appreciated that support; however, people also recognised the need for clinical expertise, which can be hard to access in a timely manner.

Personal assistants and informal carers provide a significant amount of support in the home. Opportunities for PU prevention support are perhaps more obvious for people who provide personal care, as they have opportunities to spot skin changes. However, our findings suggest that carer and PA roles can go beyond skin checks. The holistic, flexible nature of those roles means many are uniquely placed to notice and react to changes in PU risk.

Personal assistants are a vital, sometimes hidden, part of the social care workforce. Although not the original focus of this study, much of our PA participant data relate to the challenging context that PAs work within and the lack of support for both PAs and the people who employ them. Although our PA sample is relatively small, our findings are supported by wider literature. Previous research cites a range of challenges that can hinder the development of 'relationship-based care',[67] for example, PAs being asked to undertake tasks without appropriate training; expectations that PAs support the wider family; limited peer support and lack of regulation/monitoring.[68] That lack of regulation can add to a sense of isolation.[69] Retention of PAs also needs careful consideration,[70] including upskilling and flexibility in pay conditions.[71]

Personal assistants-focused PU prevention interventions need to be carefully considered within this broader picture of high workloads and low pay, where training costs may not be reimbursed and employers are often balancing tight support budgets.[72] It is therefore potentially unfair to expect PAs to undertake more professional development for free. Informal carers also provide vital, unpaid labour. Our carer findings echo Roddis *et al.*,[38] who highlight both

positive (e.g. caring two-way relationships) and negative (e.g. emotional and physical exhaustion, isolation, role conflicts and guilt) aspects of being a carer.

Reflections on the project

Fake participants

During our recruitment process, we were contacted by many ineligible participants, who we believe were pretending to have LTNC experience to claim financial incentives. The research team noticed multiple emails with similar wording; many very similar e-mail addresses and a time difference on some e-mails (indicating people may not be in the UK). Those concerns were discussed with both CIGs who helped to update recruitment processes. CIG input at this stage was invaluable, as we were keen to ensure that extra checks were done sensitively without offending genuine people.

All suspicious potential participants were asked to have a video call with cameras on, so that a researcher could see the individual and their environment. Some people declined to take part, others refused to turn on cameras and/or speak, instead using the chat function. During video calls people were asked questions about their LTNC or caring/PA role. People were also informed that they would need to provide a UK postcode to receive vouchers. If researchers were still unsure of someone's validity after that call, they were invited to meet with a second member of the team.

This multi-pronged approach led us to exclude around 90 people. The process involved a significant amount of researcher time, pulling focus from other valuable recruitment activities. Sadly, this issue is becoming more common across both research participation and PPI.[73,74] The participatory nature of this study adds an additional layer of complexity, as there was a danger that fake participants may encounter peer researchers with genuine LTNC experience, which could be distressing. We discussed this as part of peer interview training, and it was agreed that university researchers would undertake interviews with any participant who raised concerns. Thankfully, due to the process described above, we do not believe that any fake participants made it through the recruitment process to an interview.

Another consideration relates to people speaking English as a second language. We were mindful that 'odd' phrases within e-mails or confusion on calls could be due to language barriers. One potential participant gave that as a reason for using the chat function, rather than speaking. We did not want to unfairly exclude people or create additional participation barriers for an already underserved group. As such, anyone who indicated that English was not their first language was offered translated documents and an interpreter. All suspicious enquiries declined.

We recommend that all studies which offer a financial incentive establish a process for checking the eligibility of participants in a sensitive manner. The development of that process should include public contributors/peer researchers.

Operational challenges in participatory research

The operational challenges involved in participatory research and PPI are well documented.[75,76] Participatory projects do not fit neatly into existing research systems and processes, such as funding, finance, ethical approval, insurance and oversight. Cook[75] suggests that working with peer researchers can test 'bureaucratic and support systems' within research institutions, and participatory projects require additional time to navigate those issues. Our experience supports that as a significant amount of time was taken up by navigating these operational challenges and attempting to make bureaucratic or academic processes accessible to peer researchers. We are working within our host institution to share our learning regarding these issues and, where possible, create change.

One specific example relates to the formation of our steering committee. Establishing an independent oversite committee was a requirement of our funding. Given the participatory nature of the project, we proposed a cochair model with a service user and an independent senior researcher. However, we were informed by our funder that this was not within their research governance rules and that steering committees can only be chaired by someone employed in a research role. In addition, the steering committee model raised some general concerns for the team. The model values distance and independence, which is at odds with the participatory paradigm. We discussed these concerns honestly with the committee chair and considered how a steering committee may be most effective within a participatory context. It was suggested that all steering group members should have a copy of the shared values developed with CIG members and aim to hold us to account regarding how we enacted those values in practice. We also made sure that people with participatory research experience were included alongside a service user, health professional and third-sector partners. Despite our initial concerns, the steering committee was extremely helpful. For future participatory studies, we recommend thinking critically about committee membership, to ensure that members feel comfortable appraising the

quality of participatory research and to avoid epistemic injustice from both the perspective of academic/clinical knowledge and lived experience. More work is needed to understand how research governance structures may be adapted to better serve participatory studies.

Support for peer researchers

Our diverse population experience a range of complex health challenges, including physical and cognitive impairments, communication problems and fatigue. In addition, people's time and energy may be consumed with the complexities of managing their care or supporting someone else. Building inclusive research collaborations is a vital part of participatory research. However, truly authentic, democratic participation can be challenging to achieve. Flexible processes and tailored support were a vital part of building collaborations. Despite our focus on support, we still encountered challenges. For example, personal circumstances/illness meant some peer researchers took time away from the study. People also shared the emotional impact of reviewing data, which could be demanding for those who had experienced similar issues.

Facilitation is another important component of participatory research,[77] with facilitators acting as intermediaries between stakeholders, supporting research activities and individuals.[26] Despite this, we have found facilitation to be an undervalued skill in academia. Creative facilitation techniques were used to make complex research processes more accessible and engaging, for example, the use of poetry and theatre within collaborative analysis workshops. Facilitation was particularly pertinent during the systems mapping workshop, where we explored an emotive health topic across professional and service user/carer boundaries. During the workshop, we used a live, composite case study to create a starting point for discussion, which was one step removed from people's real-life experiences. The inclusion of the case study, which was told from the perspective of a service user and presented by an actor, also intended to set a user-centred, respectful tone. We received very positive feedback from workshop participants, particularly regarding the case study. However, some CIG members still found the workshop challenging and, at times, struggled to be heard among professional voices.

The university team were also mindful of potential power imbalances created by the fact that they are in salaried positions and that this project may contribute to career progression, which is not the case for peer researchers. Power dynamics and support will be further explored in our ongoing evaluation of participatory approaches.

Capacity building activities

Co-operative inquiry groups

An explicit aim of participatory research is to build capacity and networks within the communities who are the focus of the work. This was particularly evident within the work of our CIGs (see also *Impact*). For example, some CIG members volunteered to be peer interviewers, and we developed a tailored package of initial training and ongoing support throughout the interview process. Including, interview practice via role-play with an actor and each other, written materials, post-interview debriefs with the university team and practical support with administration and interview recording. Training and support for peer interviewers was vital to the success of the project and we hope the skills developed by peer interviewers will be helpful in future projects. We also believe our support package may be a helpful starting point for other teams using peer interview methods. Our learning about this process, and other elements of our participatory approach, has already been shared with other teams via local events and international conferences (see *Additional information*).

Third sector

We have developed invaluable links with third-sector organisations and learnt about how to build meaningful collaborations with those organisations. The focus on community engagement and equality, diversity and inclusion within health research has led to an increase in researchers contacting community organisations, and we have heard examples of organisations and individuals experiencing 'consultation fatigue'.[78] Therefore, we were mindful of approaching and working with third-sector partners in a respectful manner and of building reciprocal relationships, where possible. Organisations were approached with plain language information, which included the participatory nature of the study and different ways to contribute. We also stressed that we would like to build ongoing relationships and asked people if there was anything that we could offer them. Information was tailored to each organisation, making links between their remit and the research clear. Where a member of the team had an existing relationship with the organisation, the initial contact came from them.

In some instances, organisations offered valuable advice regarding how best to approach their membership. Most organisations agreed to circulate the details of the study. Some organisations went beyond sending out recruitment information on our behalf and became research partners in their own right, for example, by contributing to WP3 and WP4, helping to develop dissemination plans or becoming collaborators on the PUP@home2 grant application. We

have no doubt that this network will be a valuable asset for future studies.

Patient and public involvement

This is a participatory study, meaning people with lived experience of PU risk involved in all aspects of the research. Most notably, our CIG members have been instrumental in planning and undertaking the research. PPI forms part of a wider programme of stakeholder involvement, which includes service users, informal carers, PAs, third-sector staff, policy-makers and healthcare professionals. Our participatory approach is demonstrated throughout this synopsis and in *Appendix 1*. Here we summarise some of our key activities:

- **Research conception and design** – The idea for this research topic came from members of the Pressure Ulcer Research Service User Network (PURSUN), who have a longstanding relationship with the University of Leeds. We have built relationships, trust and capacity over time, enabling us to move from more typical PPI models to our first fully participatory study. PURSUN members contributed to grant application development through workshops and document reviews, and as co-applicants.
- **Study management and oversite** – A Project Coordination Group provided high-level management and oversight of the study and included two CIG members. A steering committee also included an independent steering committee.
- **Recruitment** – CIG members co-designed recruitment resources, including information sheets, a website, a short study summary and social media adverts. They contributed to recruitment plans, including identifying and approaching relevant third-sector organisations. We reviewed the diversity of our study population part during WP2, and CIG members helped to identify perspectives which were missing or under-represented, informing further recruitment.
- **Data collection** – CIG members co-designed interview topic guides and app tasks, and user-tested the app. A smaller group of people volunteered to undertake peer-to-peer interviews, supported by the university researchers.
- **Data analysis and interpretation** – CIG members contributed to analysis via completion of RAP sheets, reviewing data (interview recordings, transcripts and app entries) and workshops. For some, this was a challenging aspect of the study, and we worked with people to try and make the process accessible, for example, by using creative, participatory facilitation techniques to help people explore data. More detail is provided in *Appendix 2*.
- **Collaborative writing and coauthorship** – All CIG members were invited to be coauthors or to be named in the acknowledgment section of this synopsis and the related journal publication.[1] The PPI lead supported that collaborative writing process. For example, key messages for this manuscript were discussed in CIG meetings. Some people also met individually with the PPI lead to discuss the publication process and provide verbal feedback on drafts. Others provided written feedback in response to specific questions, or on drafts more generally. One person provided feedback as voice recordings due to access issues around typing. This flexible approach was time consuming but was a vital part of ensuring that peer researchers could contribute to the writing process. CIG members have played a significant role in identifying and shaping messages from this study and ensuring that our findings are written in a clear, respectful way.

Evaluation

We undertook a collaborative, iterative evaluation of our participatory approaches, involving individual and group reflection throughout the study and helping us to improve our collaboration. Some of that learning is shared throughout this synopsis (e.g. see *Operational challenges in participatory research*, *Equality, diversity and inclusion*, *Impact* and *Capacity building activities*). Further evaluation activities will continue past the study end date and full evaluation findings will be shared in separate outputs.

Public dissemination plans

Co-operative inquiry group members have shaped dissemination plans and will continue to support dissemination activities. We have built relationships with LTNCs charities and will work with them to incorporate findings into their existing formats, such as information sheets, training and newsletters. Some CIG members indicated that they would like to talk about the research at local charity and community events relevant to their conditions and interests. That dissemination will include both sharing study findings and people's experiences of peer research. To support that process, we will produce a suite of public dissemination materials that both peer and university researchers can use:

- Plain language slides.
- Plain language summary of results (this will be sent to study participants).
- Visual materials, for example map, posters and images from the 'Rivers of Life' workshop.

- Messages and discussions points for different audiences (e.g. public, professional and policy).
- Guidance on interview style presentations, whereby a university researcher interviews a peer researcher about their experience of the study and what the results mean for the public.
- Case studies – We have already developed one composite case study (a fictional case study which illustrates our findings). We will further develop that case study, and others, and explore presentation formats, including short films and written stories.

Equality, diversity and inclusion

Monitoring

Participant demographics and backgrounds are summarised in *Appendix 3*. Participants brought many different health and life experiences to this study. For example, healthcare professionals talked about caring for family members, people with LTNCs described taking on carer roles and family carers described the impact of their own health conditions. Therefore, it is challenging to describe our study population in a transparent manner, while still recognising the multifaceted and fluid nature of people's identities. Service users, carers and PAs were all asked to complete an optional demographics questionnaire, with a return rate of 66.6%. We did not ask professional stakeholder to complete a demographics questionnaire. In hindsight, this was an error and something we would include in future studies.

People with disabilities

Our project's shared values (see *Appendix 1*) include a commitment to the social model of disability, which we attempted to model throughout our recruitment, participation and peer research activities. We successfully engaged with people who have a range of disabilities, including cognitive and communication challenges.

Deprivation

We compared available participant postcodes to the 2019 Index of Multiple Deprivation. The index provides a set of deprivation measures for areas across England, based on seven domains: income, employment, education, skills

TABLE 2 Index of Multiple Deprivation

Participant ref	Index of Multiple Deprivation	Index of Multiple Deprivation
	Decile 1 most deprived, 10 least deprived	**Quintile** 1 most deprived, 5 least deprived
1	10	5
2	9	5
3	6	3
4	2	1
5	8	4
6	10	5
7	2	1
8	10	5
9	10	5
10	10	5
11	4	2
12	5	3
13	6	3
14	7	4
15	3	2
16	5	3

continued

TABLE 2 Index of Multiple Deprivation (*continued*)

Participant ref	Index of Multiple Deprivation	Index of Multiple Deprivation
17	Postcode not found	–
18	Postcode not found	–
19	5	3
20	Postcode not found	–
21	4	2
22	6	3
23	3	2
24	6	3
25	3	2
26	2	1
27	2	1
28	9	5
29	9	5
30	1	1
31	1	1
32	Postcode note found	–

and training, health, disability, crime, housing/services and living environment. *Table 2* outlines where participant postcodes fall within the index.

Table 2 indicates a good spread, including participation from people in the most deprived areas. This is important given the health inequalities noted in our findings. We utilised a number of strategies to support the participation of people with disabilities and people who experience deprivation:

- Offering multiple, flexible participation mechanisms.
- Co-designing activities with peer researchers.
- Being open to feedback and adapting processes based on the needs and wishes of individual participants.
- Providing tailored training and support for peer researchers.
- Peer-to-peer interviews.
- Creative facilitation techniques to make complex research processes accessible and engaging.
- Financial incentives.
- Being flexible with timings to accommodate work and childcare commitments.
- Lending tablets to CIG members to support IT access.

Personal assistants

We did not reach our recruitment target for PAs. PAs are chronically underserved by research, despite the vital role they play within health and social care. They are a hidden workforce[79] and can fall between the gaps in professional and user networks. They have no formal registration or regulatory body and can be excluded or missed from patient and public involvement and engagement because they are employed. We encountered some challenges with PA recruitment, in part due to the lack of research infrastructure described above. We also received some informal feedback about PA recruitment barriers. We were told that PAs are extremely busy and that they found it hard to make time for meetings or interviews. People described having to 'jump through hoops' to participate, for example read detailed participant info, have a call to check eligibility, e-mails to discuss availability and so on. Some people viewed the small financial incentive for interviews as insufficient when that additional time was considered. This feedback is particularly powerful when considered against the backdrop of unpaid labour described in our findings. It was also suggested that some PAs may not recognise or value their expertise in this field. No PAs took part in an interview and the smartphone app was the most popular participation mechanism, perhaps

reflecting their need for flexibility and fitting research around busy lives. Despite the relatively small number of PAs within our sample, we received in-depth input from PA CIG members across study, which was invaluable. We hope this project provides a foundation for further research with PAs.

Ethnicity

We acknowledge that the ethnic diversity of our research population is not representative of the clinical population. As per our protocol, we collectively reviewed the population during WP2, identifying perspectives which were missing. We then initiated recruitment at two NHS sites, with a focus on ethnic diversity. The rationale for that approach was that NHS service would have access to demographic data that third-sector organisations may not, allowing them to undertake more targeted recruitment. In addition, we contacted or recontacted charities/community groups who focus on supporting culturally diverse communities. Sadly, this targeted recruitment was unsuccessful.

We asked the principal investigator at each NHS site for feedback on recruitment challenges. One person said that geographic location meant they were not well placed to target ethnically diverse communities. A second shared that, despite being in a diverse, urban location, rehabilitation services were not well used by ethnically diverse populations, demonstrating that NHS access issues can trickle down to research participation. We have included work to address this lack of diversity in our next study, including dedicated community workshops to explore the cultural relevance and appropriateness of our proposed intervention.

Impact

PUP@home1 is the start of a programme of work that ultimately aims to reduce the number and severity of PUs in people with LTNCs and, when PUs do occur, reduce the impact on quality of life. This is an ambitious goal that requires further work along a rigorous research pathway. However, the participatory approach used in PUP@home1 explicitly embeds impact throughout the research process.[80] Through this collaborative approach, we have built partnerships, capacity and networks, empowered stakeholders, and mobilised knowledge. This has led to unanticipated impacts, sometimes known as 'ripple effects'.[53,54,81]

We have built a network of peer researchers, who have developed valuable research skills. We have also witnessed the development of knowledge and peer support within our CIGs and beyond. For example:

- One participant realised that they had a PU as a result of their involvement in the study and was able to seek appropriate management with increased confidence.
- A PA accessed PU prevention training via study networks.
- A participant told us that their involvement fostered a desire to pursue further study into disability rights and inclusion.
- A PA acknowledged the importance of peer support within the CIG and is exploring how to develop that (e.g. by setting up an online forum).
- A clinician involved in the study indicated their increased PU awareness had led to changes in their clinical practice.
- We witnessed increased empathy developing between different perspectives within our systems mapping workshop.

Importantly our participatory approach has brought together key PU prevention stakeholders to develop systems and processes which support PU prevention. Their involvement throughout this study has led to an increased understanding of different stakeholder experiences, roles and barriers/facilitators to support PU prevention. This increased understanding has fostered a culture of mutual respect and a desire to work together to make a difference. There is continued support and commitment from all stakeholders to further develop, evaluate and implement the planned intervention. This is evidenced by their involvement in the development and successful funding of the NIHR163165 Pressure Ulcer Prevention at Home 2 (PUP@home2): Self-management intervention development and user testing for people with LTNCs. Their continued support is likely to result in greater long-term sustainability of the intervention.

Our work has already been presented at national and international conferences, sharing both research findings and methodological/operational learning (see *Additional information*). Future publications will articulate the practical techniques we used to facilitate participatory approaches so that other researchers can adapt. Furthermore, our study is being used as a case study to evaluate participatory methods as part of a separate but related PhD study. This will add to the body of knowledge around participatory approaches.

Implications for decision-makers

Much of the learning from this study is being taken forward during our intervention development project, PUP@home2. However, our findings demonstrate wider systemic issues which hinder people's ability to effectively self-manage care or support others. Those complex issues

cannot be addressed by a single study or intervention. Here we focus on practice and policy recommendations that we feel fall outside our sphere of influence, and that we are therefore unable to address during PUP@home2.

1. Organisations with a remit to provide health or social care to people with LTNCs (e.g. NHS providers, councils, social services or private sector) should have clear processes that enable users to access support quickly if a PU has developed. This should be clearly communicated to service users.
2. Our findings indicate that TVNs could play a more proactive role in PU prevention for individuals with complex risk profiles. This requires a culture change within tissue viability services, which currently focus on dealing with PU treatment. This may also require additional funding or resource re-allocation.
3. Further work is needed to embed appropriate systems, processes and training that support professionals and services to routinely deliver a person-centred approach. This needs to facilitate honest conversations between professionals and service users about risk, including how it can be flexibly managed in a way that is acceptable to the individual. These discussions need to consider the physical and contextual risk factors of the individual, as well as their preferences and recognise that this could lead their informed choices being different to that of a professional.
4. Independent advocacy roles are needed to help some service users navigate extremely complex systems and processes which span public, private and third sector.
5. A review and improvements to PA support, pay, training and regulation are urgently needed. Any review should include the perspectives of both PAs and the people they support and include:
    - More opportunities for peer support for PAs – including allowing paid time for crossover between shifts, for households with multiple PAs.
    - Funded time to attend training and peer support activities.
    - Service user, carer and PA perspectives should be considered when social services review care packages. Currently, some PAs are excluded from those conversations.
    - Support to facilitate challenging conversations between PAs and employers (e.g. around role negotiation and boundary setting).

Research recommendations

Our findings facilitated the development of a ToC to underpin an interactive, multicomponent intervention. The next stage in this research pathway is to develop and user test the intervention. We are in the planning stages of this work after successfully gaining HS&DR funding. Our work will continue to draw on participatory approaches, guided by the MRC complex intervention framework and incorporate with two WPs:

- WP1 Participatory Intervention Development and Pre-Testing – Multi-stakeholder, cocreation and Evaluation groups will iteratively design, test and refine intervention component prototypes, including pre-testing within the groups and with external stakeholders.
- WP2 Full Intervention Field Test in a 'real world' context – incorporating automated data capture, semistructured interviews, and validated Health Information Technology Usability Evaluation Scale.

Following this we will formally evaluate the full intervention and develop an implementation strategy to scale up and share the intervention, ensuring it reaches people with LTNCs, who are sometimes invisible to NHS services. We will seek further funding to fully evaluate the intervention and user outcomes. Our future work will also include an increased emphasis on underserved communities, to better understand their needs in relation to PU prevention and ensure our intervention is as inclusive as possible.

Our research findings also indicate that wider systemic changes are needed to improve PU prevention and LTNC care. More research is needed regarding risk negotiation between service users and professionals, both in terms of interpersonal skills and organisational culture around risk tolerance.

In addition, we recommend methodological research around the use of apps as an ethnographic tool. For example, how does data collected via an app differ to generated via other qualitative methods (e.g. observations or interviews)? Can apps help make research more inclusive for people with particular communication needs? When apps are used in conjunction with interviews, how does that influence interview conduct, and can apps a helpful preparation tool for interviewers and interviewees?

Conclusion

Using a participatory approach, we have uncovered the complexities of managing PU prevention at home for people with LTNCs, their carers and PAs. This is set within a context of service users managing multiple, changing care needs alongside wider roles in their families and society,

necessitating a flexible approach. We identified resilience and strong problems solving skills within this population, and areas of good practice within health and social care services. However, we also found tensions in the current system. Individuals with LTNCs, and the people who support them, have variable levels of knowledge around PU risk and prevention, at times this hampers their ability to develop bespoke safe routines. Factors such as inconsistent, complex services and differing perceptions of PU risk make care escalation difficult. We also identified the important roles that that the third sector, private sector, peers, family and PAs can all play PU prevention. While we acknowledge that non-NHS support is extremely valuable, it should not replace access to hands on, clinical care in the home, when needed. In addition, informal carers and PAs need recognition, support and infrastructure to help them fulfil their vital roles, while maintaining their own well-being.

These findings are illustrated in a systems map, which helped us to consider and discuss areas that may be amenable to change and to identify potential intervention components. This was followed by the development of a ToC pathway, detailing how the intervention will lead to improved PU prevention support. The ToC and the valuable relationships developed through this research, will underpin the development and evaluation of an interactive, multicomponent PU prevention intervention.

Additional information

CRediT contribution statement

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This report is dedicated to the memory of Kay Walker, who sadly passed away during the study. Kay was instrumental in developing this study and made important contributions to many more projects. She was a valued colleague and friend and is deeply missed.

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

Ethical approval was obtained from the University of Leeds Research Ethics Committee (reference: MREC 21-069, dated 29 July 2022) and the NHS Health Research Authority (reference: 23/LO/0132, dated 27 February 2023).

Information governance statement

The University of Leeds is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, the University of Leeds is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here: https://dataprotection.leeds.ac.uk/.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/GJSC0721.

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This synopsis was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

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Award publications

This synopsis provided an overview of the research award *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 following article is published as part of the thread:

Muir D, McLarty L, Drinkwater J, Bennett C, Birks Y, Broadway-Parkinson A, *et al.* Pressure ulcer prevention for people with long-term neurological conditions (LTNCs) who self-manage care and live at home. *J Tissue Viability* 2024;**33**:753–65. https://doi.org/10.1016/j.jtv.2024.08.007

For more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR134029).

Additional outputs

Presentation: Muir D on behalf of the PUP@home team. *Time to Involve Patients, Families and Caregivers in the Prevention of Pressure Ulcers in the Community*. European Pressure Ulcer Advisory Panel (EPUAP), Lausanne, Switzerland, 2024.

Workshop: Drinkwater J, Muir D. *Peer Interviewing: The Theory, Practicalities, and Practice*. PPI Summer School, Limerick, Ireland, 2024.

Presentation: Muir D on behalf of the PUP@home Team. *The Pressure Ulcer Prevention at Home Study: A Participatory Approach*. European Pressure Ulcer Advisory Panel (EPUAP), Leeds, UK, 2023.

Poster: Muir D on behalf of the PUP@home Team. *Preparing for Peer Interviews*. International Collaboration for Participatory Health Research (ICPHR) Conference, Limerick, Ireland, 2023.

Presentation: Muir D on behalf of the PUP@home team. *The Pressure Ulcer Prevention at Home Study – A Participatory Approach*. Society of Tissue Viability, Peterborough, UK, 2023.

Presentation: Muir D, McLarty L, Coleman S on behalf of the PUP@home team. *Pressure Ulcer Prevention at Home*. Complex Intervention Methods in Health Networking Event, Leeds Unit for Complex Intervention Development (LUCID), Leeds, UK, 2023.

Presentation: Muir D. *Pressure Ulcer Prevention at Home: Preparing for Peer Interviews*. Qualitative Reflective Practice Group, Leeds, UK, 2024.

Presentation: McLarty L on behalf of the PUP@home team. *Undertaking Participatory Research: Challenges and Opportunities, Lessons from the Pressure Ulcer Prevention at Home Study*. Involving Patient Partners in Research Seminar, Leeds Unit for Complex Intervention Development (LUCID), Leeds, UK, 2024.

Presentation: Coleman S, McLarty L on behalf of the PUP@home team. *Pressure Ulcer Prevention for People with Long-Term Neurological Conditions: A Participatory Approach (PUP@Home)*. Society of Tissue Viability conference, Bradford, UK, 2025.

About this synopsis

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List of supplementary material

Report Supplementary Material 1 Rivers of Life

Report Supplementary Material 2 Mobile ethnography

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/GJSC0721).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

The supplementary materials (which include but are not limited to related publications, patient information leaflets and questionnaires) are provided to support and contextualise the publication. Every effort has been made to obtain the necessary permissions for reproduction, to credit original sources appropriately, and to respect copyright requirements. However, despite our diligence, we acknowledge the possibility of unintentional omissions or errors and we welcome notifications of any concerns regarding copyright or permissions.

Glossary

Advocacy Support that helps people to express their point of view, needs, and rights. It may involve enabling people or acting on behalf of someone (with their permission).

Co-operative inquiry group Groups who do research together because they have experience of the topic being researched.

Epistemic injustice When a person, or a group of people, isn't listened to, believed, or taken seriously, despite having relevant experience.

Health inequalities Unfair, avoidable differences in health between different groups, for example, how long people are likely to live, or the care that is available to them.

Healthcare professionals Professionals who provide care for people with long-term neurological conditions. For example nurses, general practitioners, physiotherapists, occupational therapists.

Informal carer Someone who provides support for a family member or friend because that person has a health condition.

Intervention Something which is put in place to try and improve people's health or well-being. For example, a treatment, resource, therapy, or service.

Long-term neurological condition A group of health conditions, including, but not limited to, multiple sclerosis, spina bifida, spinal cord injury, muscular dystrophy and motor neurone disease.

Mobile ethnography Using mobile devices (e.g. a phone) to capture thoughts, feelings and opinions when they happen, in real time.

Participatory research When people with experience of a particular issue come together to do their own research about that issue.

Patient and public involvement When patients or members of the public help to carry out health research.

Personal assistant A type of paid, non-clinical support worker/carer.

Policy/strategic partners People with policy, strategy or commissioning roles in health or social care organisations, for example, the National Wound Care Strategy Programme, the Tissue Viability Society, wheelchair services and integrated health and social care boards.

Pressure ulcer Damaged skin and tissue caused by pressure – sometimes called bedsores or pressure sores.

Pressure ulcer grade Pressure ulcers are graded from 1 to 4 to according to how severe they are. Grade 1 is the least serious and Grade 4 is the most serious.

Pressure Ulcer Research Service User Network A group of people with lived experience of pressure ulcers or pressure ulcer risk. The group use their experiences to help improve research and care.

Rivers of Life A creative research method where people draw and talk about a river. The river is used as a visual representation of people's journey through a particular topic.

Self-care Regular things people do to look after their own health and emotional well-being.

Service user People who use NHS or social care services. In this study, that is people with long-term neurological conditions.

Spinal injuries units Specialist hospital departments who provide care and support to people with spinal injuries.

Systems mapping/systems map Systems mapping is a research method. In this study, it means we created a big map of things that impact on pressure ulcer prevention (a systems map).

Theory of Change A description and diagram showing how and why a desired change is expected to happen in a particular context. In this study we have used it to describe how and why we think particular pressure ulcer prevention resources will help people.

Third sector A term used to describe the range of organisations that are neither public sector (e.g. NHS) nor private sector (e.g. a company that sell medical devices), for example, voluntary and community organisations, charities or self-help groups.

Tissue viability nurse Nurses who specialise in wounds.

Work packages The different stages of the research study.

List of abbreviations

CIG	co-operative inquiry group
LTNCs	long-term neurological conditions
MS	multiple sclerosis
PAs	personal assistants
PPI	patient and public involvement
PU	pressure ulcer
PURSUN	Pressure Ulcer Research Service User Network
RAP	Rapid Assessment Procedure
SB	spina bifida
SCI	spinal cord injury
SIUs	spinal injuries units
ToC	Theory of Change
WP	work package

References

1. Muir D, McLarty L, Drinkwater J, Bennett C, Birks Y, Broadway-Parkinson A, *et al*. Pressure ulcer prevention for people with long-term neurological conditions (LTNCs) who self-manage care and live at home. *J Tissue Viability* 2024;**33**:753–65.
2. Coleman SMD, McClarty L, Stubbs N, Sandoz H, Drinkwater J, Ledger L, *et al*. *Pressure Ulcer Prevention at Home Protocol*. 2022. URL: https://njl-admin.nihr.ac.uk/document/download/2041918 (accessed 30 July 2024).
3. European Pressure Ulcer Advisory Panel, National Pressure Injury Advisory Panel and Pan Pacific Pressure Injury Alliance. Treatment of Pressure Injuries. In *Prevention and Treatment of Pressure Ulcers/Injuries: Clinical Practice Guideline*. The International Guideline. EPUAP/NPIAP/PPPIA; 2019.
4. Briggs M, Collinson M, Wilson L, Rivers C, McGinnis E, Dealey C, *et al*. The prevalence of pain at pressure areas and pressure ulcers in hospitalised patients. *BMC Nurs* 2013;**12**:19. URL: www.biomedcentral.com/1472-6955/12/19 (accessed 12 March 2024).
5. Smith IL, Nixon J, Brown S, Wilson L, Coleman S. Pressure ulcer and wounds reporting in NHS hospitals in England part 1: audit of monitoring systems. *J Tissue Viability* 2016;**25**:3–15.
6. McGinnis E, Briggs M, Collinson M, Wilson L, Dealey C, Brown J, *et al*. Pressure ulcer related pain in community populations: a prevalence survey. *BMC Nurs* 2014;**13**:16.
7. 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**:20–6.
8. Coleman S, Gorecki C, Nelson EA, Closs SJ, Defloor T, Halfens R, *et al*. Patient risk factors for pressure ulcer development: systematic review. *Int J Nurs Stud* 2013;**50**:974–1003.
9. Gorecki C, Brown JM, Nelson EA, Briggs M, Schoonhoven L, Dealey C, *et al*.; European Quality of Life Pressure Ulcer Project group. Impact of pressure ulcers on quality of life in older patients: a systematic review. *J Am Geriatr Soc* 2009;**57**:1175–83.
10. Wong JK, Amin K, Dumville JC. Reconstructive surgery for treating pressure ulcers. *Cochrane Database Syst Rev* 2016;**12**:CD012032.
11. Kortebein P, Symons TB, Ferrando A, Paddon-Jones D, Ronsen O, Protas E, *et al*. Functional impact of 10 days of bed rest in healthy older adults. *J Gerontol A Biol Sci Med Sci* 2008;**63**:1076–81.
12. Bennett G, Dealey C, Posnett J. The cost of pressure ulcers in the UK. *Age Ageing* 2004;**33**:230–5.
13. Guest JF, Fuller GW, Vowden P, Vowden KR. 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**:e021769.

14. The Neurological Alliance. *The Long Term Plan for the NHS: Getting It Right for Neurology Patients*. 2018. URL: www.neural.org.uk/assets/pdfs/2018-08-long-term-plan-for-nhs.pdf (accessed 8 March 2024).

15. Coleman S, Nixon J, Keen J, Wilson L, McGinnis E, Dealey C, *et al*. A new pressure ulcer conceptual framework. *J Adv Nurs* 2014;**70**:2222–34.

16. Shiferaw WS, Akalu TY, Mulugeta H, Aynalem YA. The global burden of pressure ulcers among patients with spinal cord injury: a systematic review and meta-analysis. *BMC Musculoskelet Disord* 2020;**21**:334.

17. National Clinical Guideline Centre. *Pressure Ulcer Prevention: The Prevention and Management of Pressure Ulcers in Primary and Secondary Care (Clinical Guideline 179)*. London: National Institute for Health and Care Excellence (NICE); 2014.

18. Pinkney L, Nixon J, Wilson L, Coleman S, McGinnis E, Stubbs N, *et al*. Why do patients develop severe pressure ulcers? A retrospective case study. *BMJ Open* 2014;**4**:e004303. https://doi.org/10.1136/bmjopen-2013-004303

19. Coleman S, Rawson B, Rawson Y. Patient involvement in risk tool development. *Nurs Times* 2015;**111**:17–9.

20. Ledger L, Worsley P, Hope J, Schoonhoven L. Patient involvement in pressure ulcer prevention and adherence to prevention strategies: an integrative review. *Int J Nurs Stud* 2020;**101**:103449.

21. Ledger LJ, Worsley PR, Hope J, Schoonhoven L. Patient perceptions and understanding of pressure ulcer risk in the community: empirical research qualitative. *J Adv Nurs* 2023;**79**:3312–23.

22. Nixon J, Nelson EA, Rutherford C, Coleman S, Muir D, Keen J, *et al*. Pressure UlceR Programme Of reSEarch (PURPOSE): using mixed methods (systematic reviews, prospective cohort, case study, consensus and psychometrics) to identify patient and organisational risk, develop a risk assessment tool and patient-reported outcome Quality of Life and Health Utility measures. *Programme Grants Appl Res* 2015;**3**:1–630.

23. James Lind Alliance. *The James Lind Alliance Pressure Ulcer Partnership Top 12 Uncertainties*. University of York, Health Sciences; 2013. URL: www.jlapressureulcerpartnership.co.uk/ (accessed 16 May 2024).

24. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, *et al*. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;**90**:311–46.

25. Leask CF, Sandlund M, Skelton DA, Altenburg TM, Cardon G, Chinapaw MJM, *et al*.; GrandStand, Safe Step and Teenage Girls on the Move Research Groups. Framework, principles and recommendations for utilising participatory methodologies in the co-creation and evaluation of public health interventions. *Res Involv Engagem* 2019;**5**:2.

26. International Collaboration for Participatory Health Research. *Position Paper 1: What Is Participatory Health Research?*. 2013. URL: www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_defintion_-_version_may_2013.pdf (accessed 12 March 2024).

27. *NHS England Who Is Considered a Carer?* 2024. URL: www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including,guilt%2C%20pride%20or%20other%20reasons (accessed 6 June 2024).

28. Heron J. *Co-operative Inquiry, Research into the Human Condition*. London: SAGE Publications Ltd; 1996.

29. Institute of Development Studies. *Rivers of Life*. URL: www.participatorymethods.org/method/rivers-life (accessed 30 July 2024).

30. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995;**311**:299–302.

31. CECAN. *Participatory Systems Mapping: A Practical Guide*. URL. www.cecan.ac.uk/wp-content/uploads/2020/09/PSM-Workshop-method.pdf (accessed 2 February 2021).

32. Burns D. Participatory systemic inquiry. *IDS Bull* 2012;**43**:88–100. https://doi.org/10.1111/j.1759-5436.2012.00325.x

33. De Silva MJ, Breuer E, Lee L, Asher L, Chowdhary N, Lund C, Patel V. Theory of Change: a theory-driven approach to enhance the medical research council's framework for complex interventions. *Trials* 2014;**15**:267.

34. Breuer E, Lee L, De Silva M, Lund C. Using theory of change to design and evaluate public health interventions: a systematic review. *Implement Sci* 2016;**11**:63.

35. Vindrola-Padros C, Chisnall G, Cooper S, Dowrick A, Djellouli N, Symmons SM, *et al*. Carrying out rapid qualitative research during a pandemic: emerging lessons from COVID-19. *Qual Health Res* 2020;**30**:2192–204.

36. Baxter S, Muir D, Brereton L, Allmark C, Barber R, Harris L, *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.

37. Muir D. Public Involvement in Qualitative Research. In Brooks J, King N, editors. *Applied Qualitative Research in Psychology*. London, UK: Bloomsbury Academic; 2017. pp. 251–66.

38. Roddis J, Dyson J, Woodhouse M, Devrell A, Oakley K, Cowdell F. 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**:e080398.

39. May C, Eton DT, Boehmer KR, Gallacher K, Hunt K, MacDonald S, *et al*. Rethinking the patient: using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res* 2014;**14**:281.

40. Plsek P, Greenhalgh T. Complexity science: the challenge of complexity in health care. *BMJ* 2001;**323**:625–8.

41. Haggerty JL. Ordering the chaos for patients with multimorbidity. *BMJ* 2012;**345**:e5915.

42. Griese L, Berens EM, Nowak P, Pelikan JM, Schaeffer D. Challenges in navigating the health care system: development of an instrument measuring navigation health literacy. *Int J Environ Res Public Health* 2020;**17**:5731.

43. Montori VM. Turning away from industrial health care toward careful and kind care. *Acad Med* 2019;**94**:768–70.

44. Kuluski K, Ho JW, Hans PK, Nelson M. Community care for people with complex care needs: bridging the gap between health and social care. *Int J Integr Care* 2017;**17**:2.

45. Hui A, Latif A, Hinsliff-Smith K, Chen T. Exploring the impacts of organisational structure, policy and practice on the health inequalities of marginalised communities: Illustrative cases from the UK healthcare system. *Health Policy* 2020;**124**:298–302.

46. McGraw CA. Nurses' perceptions of the root causes of community-acquired pressure ulcers: application of the model for examining safety and quality concerns in home healthcare. *J Clin Nurs* 2019;**28**:575–88.

47. Soegaard K, Sig JR, Nielsen C, Verhaeghe S, Beeckman D, Biering-Sorensen F, Sorensen JA. '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**:50–9.

48. Floríndez LI, Carlson ME, Pyatak E, Blanchard J, Cogan AM, Sleight AG, *et al*. A qualitative analysis of pressure injury development among medically underserved adults with spinal cord injury. *Disabil Rehabil* 2020;**42**:2093–9.

49. Coleman S, Greenhalgh J, Schoonhoven L, Twiddy M, Nixon J. Using PURPOSE-T in clinical practice: a realist evaluation. *J Tissue Viability* 2024;**33**:672–80.

50. Lawton R, Robinson O, Harrison R, Mason S, Conner M, Wilson B. 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**:382–8.

51. Shanley E, Patton D, Avsar P, O'Connor T, Nugent L, Moore Z. 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**:754–64.

52. Fricker M. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford, UK: Oxford University Press; 2007.

53. Carel H, Kidd IJ. Epistemic Injustice in Medicine and Healthcare. In Kidd IJ, Medina J, Pohlhaus G, editors. *The Routledge Handbook of Epistemic Injustice*. 1st edn. London, UK: Routledge; 2017.

54. Mooney R, Dempsey C, Brown BJ, Keating F, Joseph D, Bhui K. Using participatory action research methods to address epistemic injustice within mental health research and the mental health system. *Front Public Health* 2023;**11**:1075363.

55. Blease C, Carel H, Geraghty K. Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome. *J Med Ethics* 2017;**43**:549–57.

56. Birthwrights. *Systemic Racism, Not Broken Bodies: An Inquiry into Racial Injustice and Human Rights in UK Maternity Care*. 2022. URL: https://birthrights.org.uk/wp-content/uploads/2022/05/Birthrights-inquiry-systemic-racism-May-22-web-1.pdf (accessed 30 July 2024).

57. NHS England. *Action Required to Tackle Health Inequalities in Latest Phase of COVID-19 Response and Recovery*. URL: www.england.nhs.uk/about/equality/equality-hub/national-health-care-inequalities-improvement-programme/what-are-healthcare-inequalities/action-required-to-tackle-health-inequalities-in-latest-phase-of-covid-19-response-and-recovery/2024 (accessed 30 July 2024).

58. The Health Foundation. *Quantifying Health Inequalities in England*. 2022. URL: www.health.org.uk/news-and-comment/charts-and-infographics/quantifying-health-inequalities (accessed 30 July 2024).

59. Towfighi A, Berger RP, Corley AMS, Glymour MM, Manly JJ, Skolarus LE. Recommendations on social determinants of health in neurologic disease. *Neurology* 2023;**101**:S17–26.

60. WHO. *Disability*. WHO. URL: www.who.int/news-room/fact-sheets/detail/disability-and-health (accessed 30 July 2024).

61. Healthwatch. *Third of People in England Lack Confidence They Can Access Critical NHS Services Healthwatch*. 2023. URL: www.healthwatch.co.uk/news/2023-09-12/third-people-england-lack

-confidence-they-can-access-critical-nhs-services (accessed 30 July 2024).

62. Veena R. *The Health of People from Ethnic Minority Groups in England*. 2021. URL: www.kingsfund.org.uk/insight-and-analysis/long-reads/health-people-ethnic-minority-groups-england (accessed 30 July 2024).
63. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011;**155**:97–107.
64. Cabinet Office. *Race Disparity Audit: Summary Findings from the Ethnicity Facts and Figures Website*. London: Cabinet Office; 2017.
65. Oozageer Gunowa N, Hutchinson M, Brooke J, Jackson D. Pressure injuries in people with darker skin tones: a literature review. *J Clin Nurs* 2018;**27**:3266–75.
66. Madden M. Alienating evidence based medicine vs. innovative medical device marketing: a report on the evidence debate at a Wounds conference. *Soc Sci Med* 2012;**74**:2046–52.
67. Woolham J, Samsi K, Norrie C, Manthorpe J. *The Impact of the Coronavirus (Covid-19) on People Who Work as Social Care Personal Assistants*. London: NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London; 2020.
68. Manthorpe J, Woolham J, Norrie C, Samsi K. Family matters: personal assistants' experiences of engaging and working with their employers' families. *Int J Care Caring* 2020;**4**:497–511.
69. Woolham J, Norrie C, Samsi K, Manthorpe J. *Roles, Responsibilities, and Relationships: Hearing the Voices of Personal Assistants and Directly Employed Care Workers*. London: NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London; 2019.
70. Bushnik T, Wright J, Burdsall D. Personal attendant turnover: association with level of injury, burden of care, and psychosocial outcome. *Top Stroke Rehabil* 2007;**12**:66–76.
71. Wallace S, Llewellyn M, Garthwaite T, Randall H, Sullivan S. *Research on the Employment of Personal Assistants in Social Care*. Cardiff: Welsh Government; 2022.
72. Woolham J, Norrie C, Samsi K, Manthorpe J. The employment conditions of social care personal assistants in England. *J Adult Prot* 2019;**21**:296–306.
73. Ridge D, Bullock L, Causer H, Fisher T, Hider S, Kingstone T, *et al*. 'Imposter participants' in online qualitative research, a new and increasing threat to data integrity? *Health Expect* 2023;**26**:941–4
74. Health and Care Research Wales, the National Institute for Health and Care Research (NIHR), CSO. *Guidance for Recognising and Addressing Ineligible Public Involvement in Health and Social Care*. Cardiff: Health and Care Research Wales; 2024.
75. Cook T. Where participatory approaches meet pragmatism in funded (health) research: the challenge of finding meaningful spaces. *Forum Qual Sozialforsch* 2012;**13**.
76. NIHR. *A Practical Guide to Being Inclusive in Public Involvement in Health Research*. Lessons learnt from the Reaching Out programme Southampton, UK: NIHR; 2021.
77. Abma T. *Participatory Research for Health and Social Well-Being*. Switzerland: Springer; 2019.
78. Cannon V, Caunt S, Darton A, Smith C, Muir D, Nicholson P. Gypsy and Traveller-led Research *Partnerships: Reaching Out*. NIHR; 2023. URL: https://arc-yh.nihr.ac.uk/resources/blogs/gypsy-and-traveller-led-research-partnerships-reaching-out/ (accessed 12 March 2024).
79. Maddison J, Brooks J, Graham K, Birks Y. 'They exist but they don't exist': personal assistants supporting physically disabled people in the workplace. *Work Employ Soc* 2023;**37**:1052–69.
80. Springett J. Impact in participatory health research: what can we learn from research on participatory evaluation? *Educ Action Res* 2017;**25**:560–74.
81. Nobles J, Wheeler J, Dunleavy-Harris K, Holmes R, Inman-Ward A, Potts A, *et al*. Ripple effects mapping: capturing the wider impacts of systems change efforts in public health. *BMC Med Res Methodol* 2022;**22**:72.

Appendix 1 Co-operative inquiry group Partnership Agreement

Pressure Ulcer Prevention at Home

Service User, Carer and PA Research Groups

Partnership Agreement

About this document

This document sets out how we want to work together and run the project. It has been developed collaboratively by group members. It is a living document that we will revisit and update.

Our shared values

These values will underpin all our work together. We care about

- creating a space where everyone feels safe
- the power of personal stories
- honesty and openness
- transparent, democratic processes
- enjoying activities
- privacy – people own their own stories
- developing inclusive research – are the right people in the room?
- constructive challenge
- being authentic and true to ourselves
- good-quality research
- being non-judgemental and checking/challenging assumptions
- valuing different types of expertise (e.g. personal, research, clinical)
- learning from each other
- flexibility
- meaningful involvement of services users and carers
- delivering what we set out to do
- improving PU prevention and care
- improving the lives of disabled people
- practical outcomes that make a difference to people's lives
- the social model of disability.

Project aim

To find out what people need to help them prevent PUs at home (focusing on people with LTNCs, their carers and PAs).

How we want to work together

Overall approach

This is a flexible project. Activities will be designed around the needs, wishes and strengths of those involved. Group members do not have to take part in all activities. People can volunteer for things which best suit their skills and interests. Group members are free to stop or pause their involvement at any time.

We recognise and respect that people work in different ways. We will use a range of facilitation/commination approaches, to help people contribute for example talking in pairs, larger group discussions, turn taking, arts based activities and writing.

Meeting arrangements

Wherever possible, we will book meeting dates at least 3 months in advance. However, there may be some ad hock things, which comes up unexpectedly. We will use a mix of online, face to face and hybrid meetings. Online meetings will primarily be used for shorter sessions, which focus on project management. Face-to-face/hybrid sessions will be used for activities which take longer and need more of a workshop-based approach (e.g. data analysis, interview training). All meetings will include time for discussion, not just giving information. Face-to-face meetings will be held in a fully accessible venue, with parking and refreshments.

Communication between meetings

We will ask each individual for permission to share their e-mail address with the rest of the group. University staff will not share contact details without permission. Where an e-mail topic needs some discussion, we will copy in everyone who has given their permission to share details. Where an e-mail is just sharing info (e.g. meeting dates), we will blind copy everyone. Group members will not 'reply all' unless the e-mail is relevant to the project and the wider group.

Feedback and reflection

At the end of each meeting, we will take some time to reflect on how things are going. We will also provide opportunities for individual reflection and feedback for example by e-mails or conversations between meetings.

Confidentiality

If group members share discussions outside of the project, they will not use people's names (unless they have explicit permission). There may be times when people want their name to be associated with the project or with something they have said. Group members have the right to be recognised for their contributions.

We will respect the privacy of everyone involved in the project (including interview, app and focus group participants). We will not share names, or any identifiable information outside of the project team, without explicit permission. When looking at interview and app data, group members will follow the University of Leeds guidance on data security.

Decision-making

We aim to discuss things and come to a decision together. That includes seeking input from group members who are not present at a particular meeting. We may also seek advice from outside of this group. All decisions will be guided by our shared values and the project aims. If we cannot agree, we will vote.

What happens if something goes wrong?

Wherever possible, we will try to resolve conflict or negative experiences together. If group members would like to speak to someone privately, they can contact a member of university staff. If they would like to speak to someone from outside this group, they can contact the chair of the project steering committee.

COVID-19 and other infection concerns

Group members will not come to face-to-face meetings if they are feeling unwell. We will use venues with ventilation and space. People are free to wear a mask, without fear of judgement. Wherever possible, we will provide hybrid meeting facilities so that people can join online, as well as face to face.

Rights and responsibilities

All group members are responsible for

- Respecting, supporting and encouraging each other.
- Being flexible and open to change.
- Responding to e-mails/calls in a timely manner.
- Submitting fees and expenses (including receipts).
- Declaring payments to His Majesty's Revenue and Customs/Department for Work and Pensions, if needed.
- Promoting the project and sharing our learning with others.
- Respecting other people's privacy.
- Speaking up if things are not working.
- Volunteering for activities which best suit their interest and skills (e.g. project management, interviewing, data analysis, planning/ leading workshops).
- Delivering what we said we would do in the funding application.

University staff are responsible for

- Processing fees and expenses quickly.
- Signposting to information about tax and benefits.
- Making sure that the research has the right approvals and governance in place.
- Managing project finances.
- Communicating with our funders (NIHR).
- General project administration – for example booking meeting rooms, preparing agendas, witting up notes, storing data appropriately and so on.
- Sending out meeting documents in plenty of time.
- Providing support to group members between meetings, as needed.
- Monitoring the project timelines.

The University of Leeds holds the budget for this project and holds responsibility/liability for some aspects of the work. However, staff members will be open and honest about work that happens between meetings and provide regular updates to the group. Group members have the right to ask for information about (or involvement in) any aspect of this project.

Meeting ground rules

- Show respect for each other's views.
- Challenge constructively.
- Allow time for others to speak.
- Respect people's personal space.
- Start and end on time.
- It's OK to disagree!
- Respect confidentiality.
- Avoid jargon and acronyms, or explain what you mean.
- There is no such thing as a stupid question.
- Do not point out spelling or grammar mistakes.
- No pressure to contribute.
- Anyone can suggest agenda items.

Appendix 2 Data collection and analysis

Overall approach

Iterative, participatory approach with data collection and analysis happening concurrently and emerging findings from each WP informing the next. Multiple participation mechanisms were offered, with some people choosing to participate across multiple WPs. Analysis drew on the principles of rapid qualitative research and framework analysis. Emerging themes from early CIG discussions were used to create RAP sheets. RAP sheets are a tool used to summarise emerging findings and share those within a research team and with external stakeholders. They provide a template for notes, highlighting important ideas which can then be explored by the team in more depth. RAP sheet headings were reviewed as new data were generated. The RAP sheet headings were then agreed and formed the basis of a framework for collaborative framework analysis. A range of participatory facilitation techniques were utilised to help peer researchers explore and make meaning from data in an accessible way.

Data sources

1. CIG meetings/workshops (all WPs)
   a. RAP sheets
   b. Recordings
   c. Workshop notes

2. Interviews (WP2)
   a. RAP sheets
   b. Audio
   c. Transcripts

3. Fieldnotes App (WP2)
   a. App entries (text, audio and images)
   b. RAP sheets

4. Stakeholder workshop (WP3)
   a. RAP sheets
   b. Recording
   c. Transcript

5. Systems mapping workshop (WP4)
   a. Draft maps
   b. Workshop notes
   c. Recordings

Each column in *Table 3* shows how data from different participant groups were collected, managed and analysed, including the points where different data sources were brought together.

Black text describes the activity; blue text describes the purpose of that activity.

TABLE 3 Data table

CIG participant data	Interview only participant data	App only participant data	Interview and app participant data	Stakeholder workshop participant data	Systems mapping workshop data
CIG members shared personal experiences and looked for common themes together via Rivers of Life exercise and facilitated discussion Data collection Collaborative analysis					
2 × RAP sheet agreed by CIG members (one for people with LTNCs/ informal carers and one for PAs) Preparing for further data collection					
App tasks and interview topic guides agreed Preparing for further data collection					
		App tasks competed Data collection	App tasks completed Data collection		
		App monitored by two researchers (peer and university) who are keep notes and send follow-up questions Data collection Individual analysis	App monitored by two researchers (peer and university) who are keep notes and send follow-up questions Data collection Individual analysis		

continued

TABLE 3 Data table (*continued*)

CIG participant data	Interview only participant data	App only participant data	Interview and app participant data	Stakeholder workshop participant data	Systems mapping workshop data
			Interviewer reviews participant app entries and completes RAP sheet Interview prep Individual analysis		
	Interview completed and transcribed Data collection		Interview completed and transcribed Data collection	Workshop(s) completed and transcribed Data collection	
	RAP sheet completed by interviewer Individual analysis		Existing RAP sheet updated by interviewer – using different colour to track changes over time Individual analysis	RAP sheet completed by facilitators Individual analysis	
	Initial sharing/discussion of RAP sheet via university team meetings and CIG meetings. If appropriate, RAP sheets updated during discussions, using different colour to show changes over time. RAP sheet headings refined in response to new data. Final RAP sheet headings become framework for the next stage of analysis Data emersion Collaborative analysis Encouraging reflexivity	Initial sharing/discussion of researcher observations/reflections via university team meetings and CIG meetings. RAP sheet headings refined in response to new data. Final RAP sheet headings become framework for the next stage of analysis Data emersion Collaborative analysis Encouraging reflexivity	Initial sharing/discussion of RAP sheet via university team meetings and CIG meetings. If appropriate, RAP sheets updated during discussions, using different colour to show changes over time. RAP sheet headings refined in response to new data. Final RAP sheet headings become framework for the next stage of analysis Data emersion Collaborative analysis Encouraging reflexivity	Initial sharing/discussion of RAP sheet via university team meetings and CIG meetings. If appropriate, RAP sheets updated during discussions, using different colour to show changes over time. RAP sheet headings refined in response to new data. Final RAP sheet headings become framework for the next stage of analysis Data emersion Collaborative analysis Encouraging reflexivity	
	NVivo (QSR International, Warrington, UK) Entry 1 – RAP sheet data entered into NVivo framework Data management	NVivo entry 1 – RAP sheet data entered into NVivo framework Data management	NVivo Entry 1 – RAP sheet data entered into NVivo framework Data management	NVivo Entry 1 – RAP sheet data entered into NVivo framework Data management	

TABLE 3 Data table (*continued*)

CIG participant data	Interview only participant data	App only participant data	Interview and app participant data	Stakeholder workshop participant data	Systems mapping workshop data
CIG members invited to review data that they were not involved in collecting (a RAP sheet, transcript, recording or app entries) Reviewers make notes which were shared at CIG meetings. Where appropriate RAP sheets updated in a different colour to show changes over time Data emersion Individual analysis	CIG members invited to review data that they were not involved in collecting (a RAP sheet, transcript, recording or app entries) Reviewers make notes which were shared at CIG meetings. Where appropriate RAP sheets updated in a different colour to show changes over time Data emersion Individual analysis	CIG members invited to review data that they were not involved in collecting (a RAP sheet, transcript, recording or app entries) Reviewers make notes which were shared at CIG meetings. Where appropriate RAP sheets updated in a different colour to show changes over time Data emersion Individual analysis	CIG members invited to review data that they were not involved in collecting (a RAP sheet, transcript, recording or app entries) Reviewers make notes which were shared at CIG meetings. Where appropriate RAP sheets updated in a different colour to show changes over time Data emersion Individual analysis	CIG members invited to review data that they were not involved in collecting (a RAP sheet, transcript, recording or app entries) Reviewers make notes which were shared at CIG meetings. Where appropriate RAP sheets updated in a different colour to show changes over time Data emersion Individual analysis	
2 × collaborative analysis workshops with each CIG – bringing together data from across different sources. Workshop 2 – looking for example which support/challenge the framework headings. Poetry exercise to help explore a transcript. Workshop notes captured on flipcharts and a RAP sheet. Workshop 2 – creating a composite case study/studies which brings key themes to life Collaborative analysis Triangulation Encouraging reflexivity Preparing for systems mapping	2 × collaborative analysis workshops each CIG – bringing together data from across different sources. Workshop 2 – looking for example which support/challenge the framework headings. Poetry exercise to help explore a transcript. Workshop notes captured on flipcharts and a RAP sheet. Workshop 2 – creating a composite case study/studies which brings key themes to life Collaborative analysis Triangulation Encouraging reflexivity Preparing for systems mapping	2 × collaborative analysis workshop with each CIG – bringing together data from across different sources. Workshop 2 – looking for example which support/challenge the framework headings. Poetry exercise to help explore a transcript. Workshop notes captured on flipcharts and a RAP sheet. Workshop 2 – creating a composite case study/studies which brings key themes to life Collaborative analysis Triangulation Encouraging reflexivity Preparing for systems mapping	2 × collaborative analysis workshops with each CIGs – bringing together data from across different sources. Workshop 1 – looking for example which support/challenge the framework headings. Poetry exercise to help explore a transcript. Workshop notes captured on flipcharts and a RAP sheet. Workshop 2 – creating a composite case study/studies which brings key themes to life Collaborative analysis Triangulation Encouraging reflexivity Preparing for systems mapping	2 collaborative analysis workshops with CIGs – bringing together data from across different sources. Workshop 1 – looking for example which support/challenge the framework headings. Poetry exercise to help explore a transcript. Workshop notes captured on flipcharts and a RAP sheet. Workshop 2 – creating a composite case study/studies which brings key themes to life Collaborative analysis Triangulation Encouraging reflexivity Preparing for systems mapping	
NVivo entry 2 – update and combine service user/carer and PA frameworks Data management	NVivo entry 2 – update and combine service user/carer and PA frameworks Data management	NVivo entry 2 – update and combine Service user/carer and PA frameworks Data management	NVivo entry 2 – update and combine service user/carer and PA frameworks Data management	NVivo entry 2 – update and combine service user/carer and PA frameworks Data management	

continued

TABLE 3 Data table (*continued*)

CIG participant data	Interview only participant data	App only participant data	Interview and app participant data	Stakeholder workshop participant data	Systems mapping workshop data
Draft narrative summary written for each theme, including participant quotes. Written by university researcher based on CIG workshop discussions. Reviewed and refined by CIG members. Summaries cross referenced with NVivo Validation Member checking Crafting the message Preparing for systems mapping	Draft narrative summary written for each theme, including participant quotes. Written by university researcher based on CIG workshop discussions. Reviewed and refined by CIG members. Summaries cross referenced with NVivo Validation Member checking Crafting the message Preparing for systems mapping	Draft narrative summary written for each theme, including participant quotes. Written by university researcher based on CIG workshop discussions. Reviewed and refined by CIG members. Summaries cross referenced with NVivo Validation Member checking Crafting the message Preparing for systems mapping	Draft narrative summary written for each theme, including participant quotes. Written by university researcher based on CIG workshop discussions. Reviewed and refined by CIG members. Summaries cross referenced with NVivo Validation Member checking Crafting the message Preparing for systems mapping	Draft narrative summary written for each theme, including participant quotes. Written by university researcher based on CIG workshop discussions. Reviewed and refined by CIG members. Summaries cross referenced with NVivo Validation Member checking Crafting the message Preparing for systems mapping	
					Systems mapping workshop Composite case study used to share themes from across previous WPs. Small group work – adding to draft systems map. Potential intervention components discussed. Group discussions captured via post it notes, maps and recordings Data collection Triangulation Collaborative analysis
					First draft of systems map and ToC developed by university researchers, using workshop notes and recordings. Refined via multiple rounds of feedback from workshop participants and CIG members Individual analysis Member checking Preparing dissemination materials

Appendix 3 Participant characteristics

Characteristics of participants are described in *Table 4*.

TABLE 4 Long-term neurological conditions, informal carers, PAs

Number	Service user	Carer	PA	Experience of a LTNC and other conditions	Caring experience	PU experience[a] Y/N	Age	Ethnicity	Religion	Contribution to the study
1	Y	Y		MS, fibromyalgia, epilepsy, hypothyroidism, osteoarthritis, heart issues, depression	MS, type 1 diabetes	Y	65–70	White[b]	No religion	CIG, app, systems mapping
2	Y	Y		SCI	CP	Y	45–50	White	Christian	CIG, app
3			Y		FND	N	65–70	White	Christian	CIG, systems mapping
4			Y		SB, MD, CP, PMLD	Y	25–29	White	No religion	CIG, stakeholder group
5	Y			Chronic fatigue	MS	Y	65–70	White	Christian	CIG, systems mapping
6	Y	Y		SCI, post-SCI trauma, syringomyelia, acute and chronic musculo-skeletal issues		Y	50–54	White	Christian	CIG, systems mapping
7	Y			SB		Y	55–60	White	Christian	CIG, systems mapping
8		Y			SB	Y	55–60	White	Christian	CIG, systems mapping
9	Y			SB and hydrocephalus		Y	30–34	Black Caribbean	Christian	CIG
10	Y			SB		Y				CIG
11	Y			SB						CIG
12		Y			SB					CIG
13		Y								CIG
14	Y									CIG
15 Withdrew			Y							CIG
16 Withdrew	Y			SB						CIG
17	Y			SCI		Y	40–44	White	No religion	App, interview
18	Y			MD						App, interview
19	Y			SCI		N	75 or over	White	Christian	Interview
20	Y			SCI		N	60–64	White	No religion	App, interview
21		Y			SCI	Y	50–54	White	Christian	App, interview
22	Y	Y	Y		ME	N	55–60	White	Buddhist	App
23	Y			SCI		Y	30–34	White	No religion	App

continued

TABLE 4 Long-term neurological conditions, informal carers, PAs (*continued*)

Number	Service user	Carer	PA	Experience of a LTNC and other conditions	Caring experience	PU experience[a] Y/N	Age	Ethnicity	Religion	Contribution to the study
24		Y		SB		Y	60–64	White	Christian	Interview
25	Y			SB						Interview
26	Y			SCI						App, interview
27	Y			SCI		Y	45–50	White	Christian	App
28	Y			CP						App, interview
29		Y	Y	MD						App
30 Withdrew			Y		MS					Interview
31	Y			SB, SCI		Y	50–54	White other	Christian	Interview
32	Y			Intercranial hypotension		Y	40–44	White	Christian	App, interview
33	Y			SCI		Y	35–40	White	No religion	Interview
34	Y			MND		N	60–64	White	No religion	App
35 Withdrew			Y		MND, MS					Interview
36	Y			SCI						Interview
37	Y			Spinal fusion, kyphosco-liosis idiopathic, spinal stenosis		Y	60–64	White	Other	App
38	Y			SCI		Y	45–50	White	No religion	Interview
39	Y			MND		N	75 or over	White	Other	App, interview
40	Y			SB, hydrocephalus epilepsy		Y	35–40	White	No religion	Interview
41	Y			SB, MND		Y	55–60	White	Christian	App, interview
42	Y			SCI		N	60–64	White	No religion	Interview
43		Y			SCI	Y	55–60	White	Christian	Interview
44 Withdrew										
45		Y	Y		CP	Y	50–54	White	Christian	App
46		Y			SB	Y	65–70	White	No religion	Interview
47			Y		Undefined neurological condition					App
48			Y		SMA	N	30–34	White	No religion	App

CP, cerebral palsy; FND, functional neurological disorder; MD, muscular dystrophy; ME, myalgic encephalomyelitis; MND, motor neurone disease; PMLD, profound and multiple learning disability; SMA, spinal muscular atrophy.
a Experience of having a PU and/or caring for someone with a PU.
b Unless otherwise stated 'White' is White British (English/Welsh/Scottish/Northern Irish).

Professional and strategic stakeholders who participated in the study are listed in *Table 5*.

TABLE 5 Professional and strategic stakeholders

Number	Organisation type	Role	Contribution to the study
1	Wheelchair services	Neuro Physiotherapist	Stakeholder group, systems mapping
2	Wheelchair services	Occupational Therapist	Stakeholder group
3	NHS Trust	Clinical Nurse Specialist, Tissue Viability	Stakeholder group, systems mapping
4	NHS Trust	Clinical Specialist Physiotherapist	Systems mapping
5	NHS Trust	Nurse Consultant, Tissue Viability	Systems mapping
6	Integrated Care Board	Head of Quality Improvement	Systems mapping
7	University Health Board	Rehabilitation Engineering	Systems mapping
8	University Health Board	Rehabilitation Engineering	Systems mapping
9	Community Trust, NHS Trust	Patient Safety Specialist	Systems mapping
10	Community Trust, NHS Trust	Physiotherapist	Stakeholder group, systems mapping
11	Community Trust, NHS Trust	Occupational Therapist	Stakeholder group
12	Community Trust, NHS Trust	Specialist Neurology Nurse	Stakeholder group
13	Community Trust, NHS Trust, University	TVN specialist, Senior Lecturer in Tissue Viability	Stakeholder group
14	Primary Care	General Practice Nurse	Stakeholder group, systems mapping
15	Primary Care and University	GP, Clinical Academic	Stakeholder group, systems mapping, CIG
16	Third sector	Service Development, Engagement	Stakeholder group, systems mapping
17	Third sector	Service Development, Engagement	Systems mapping
18	Third sector	Service Development, Engagement	Systems mapping
19	Private sector	Occupational Therapist	Stakeholder group
20	Private sector, NHS	Occupational Therapist	Systems mapping
21	Independent (retired)	TVN	Systems mapping
22	University	Head of Occupational Therapy	Systems mapping
23	University	Professor of Tissue Viability, Nurse	Systems mapping
24	University	Associate Professor of Applied Clinical Research, Nurse	Stakeholder group, systems mapping, CIG
25	University	Public Involvement and Engagement Lead	Systems mapping, CIG
26	University	Research Fellow (Skin)	Stakeholder group, systems mapping, CIG

GP, general practitioner.

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Appendix 4 Systems map clusters

This section provides maps with larger text, which focus on different clusters of information as follows:

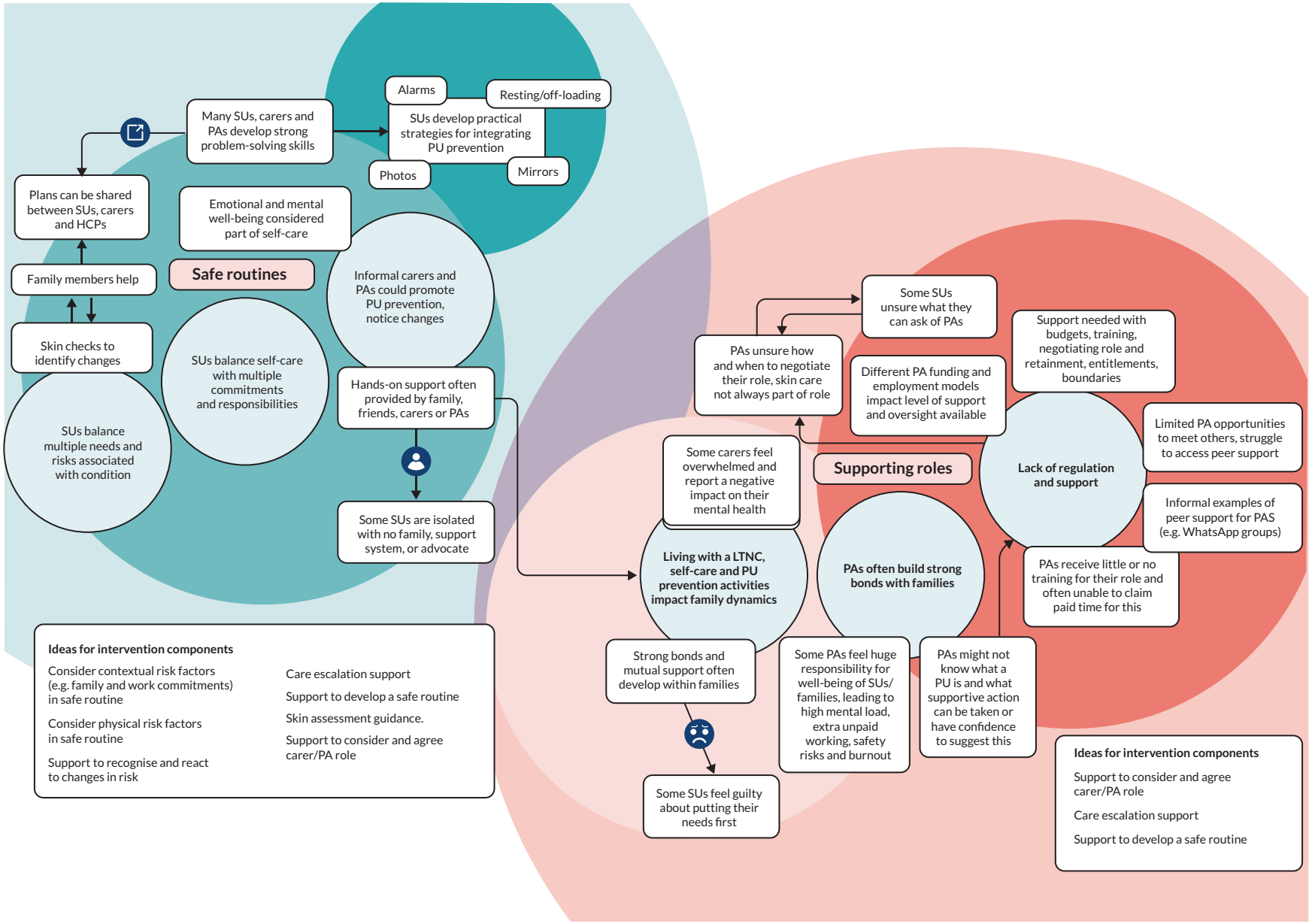

FIGURE 4 Safe routines and supporting roles. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

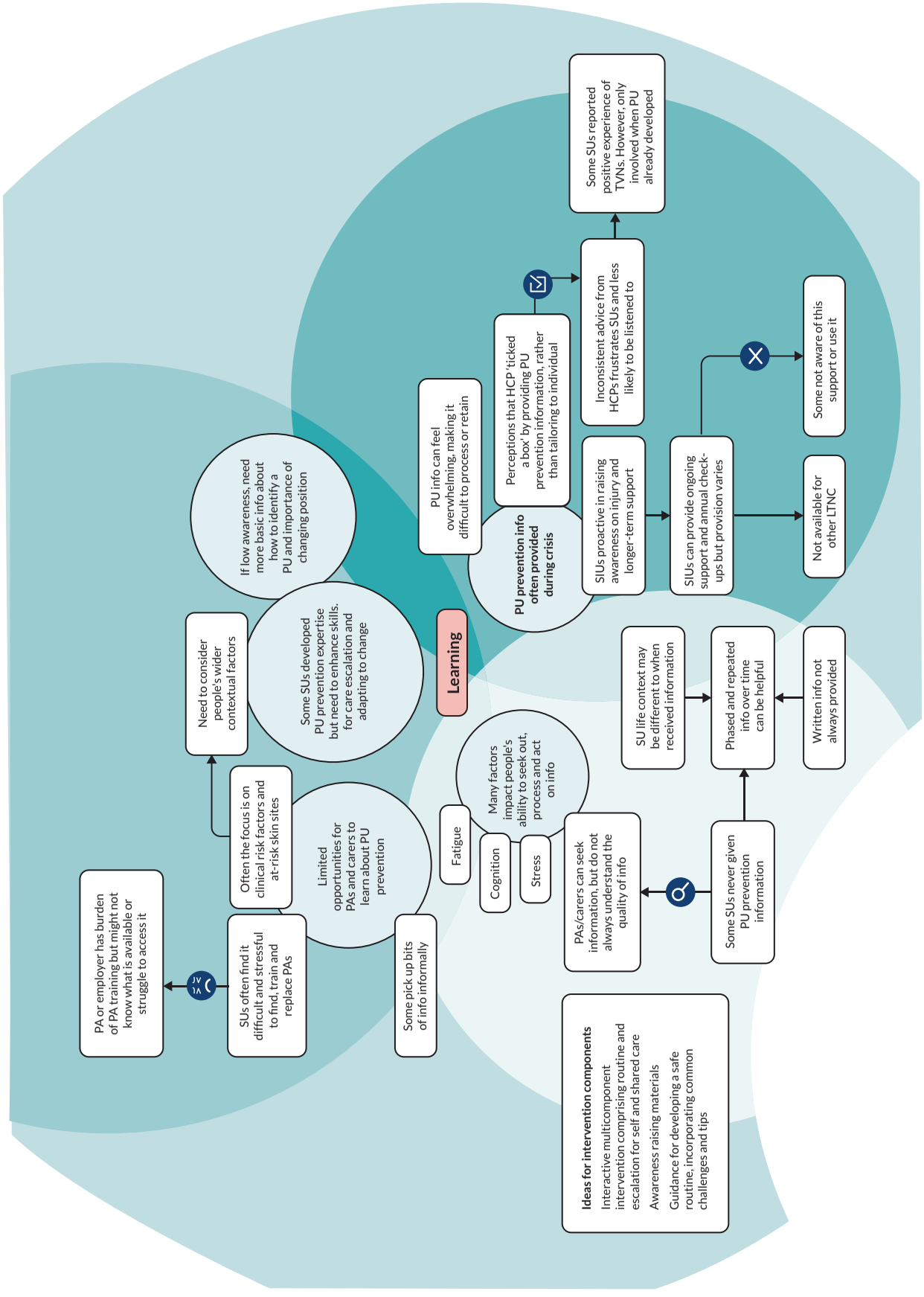

FIGURE 5 Learning. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

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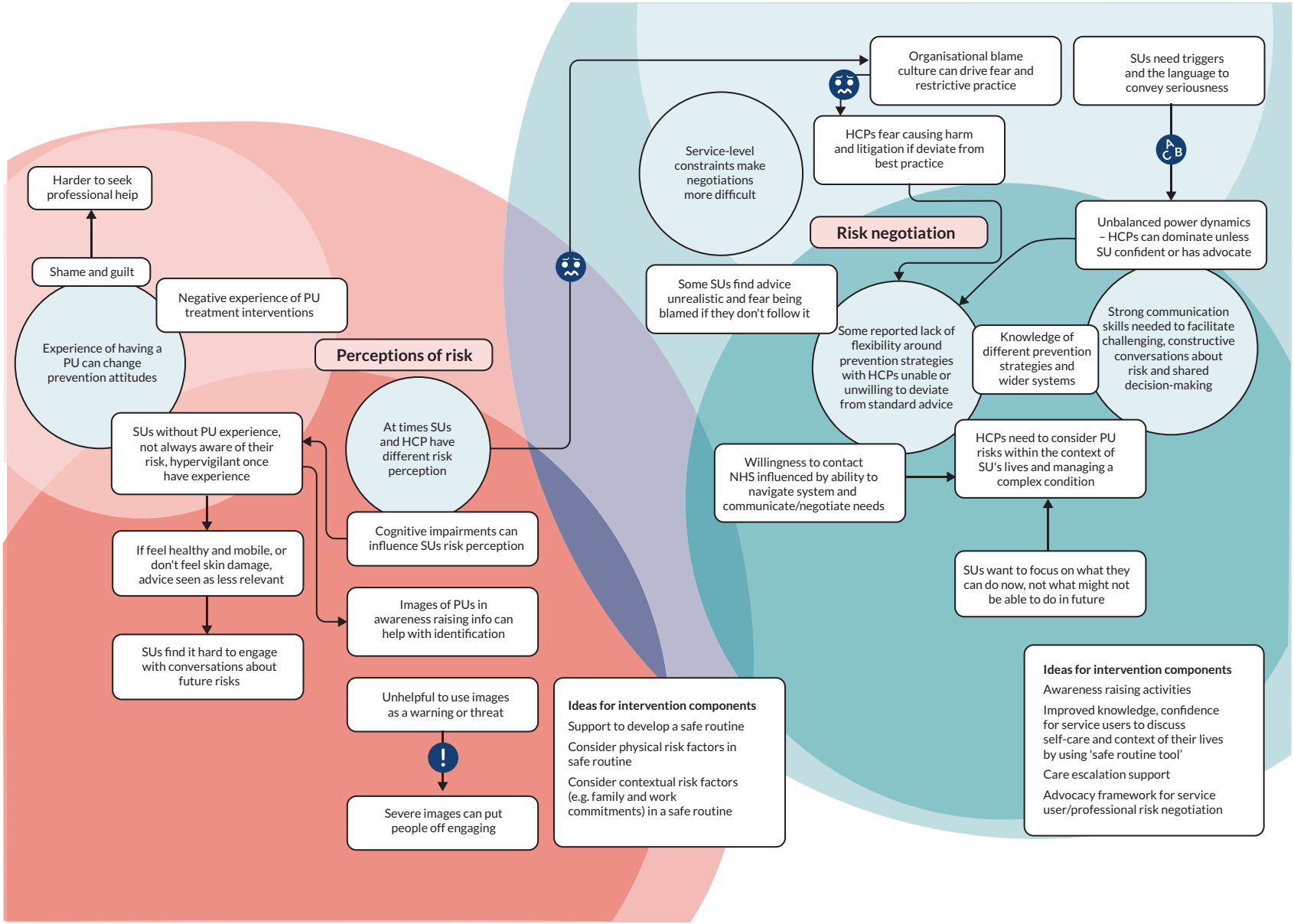

FIGURE 6 Perceptions of risk and risk negotiation. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

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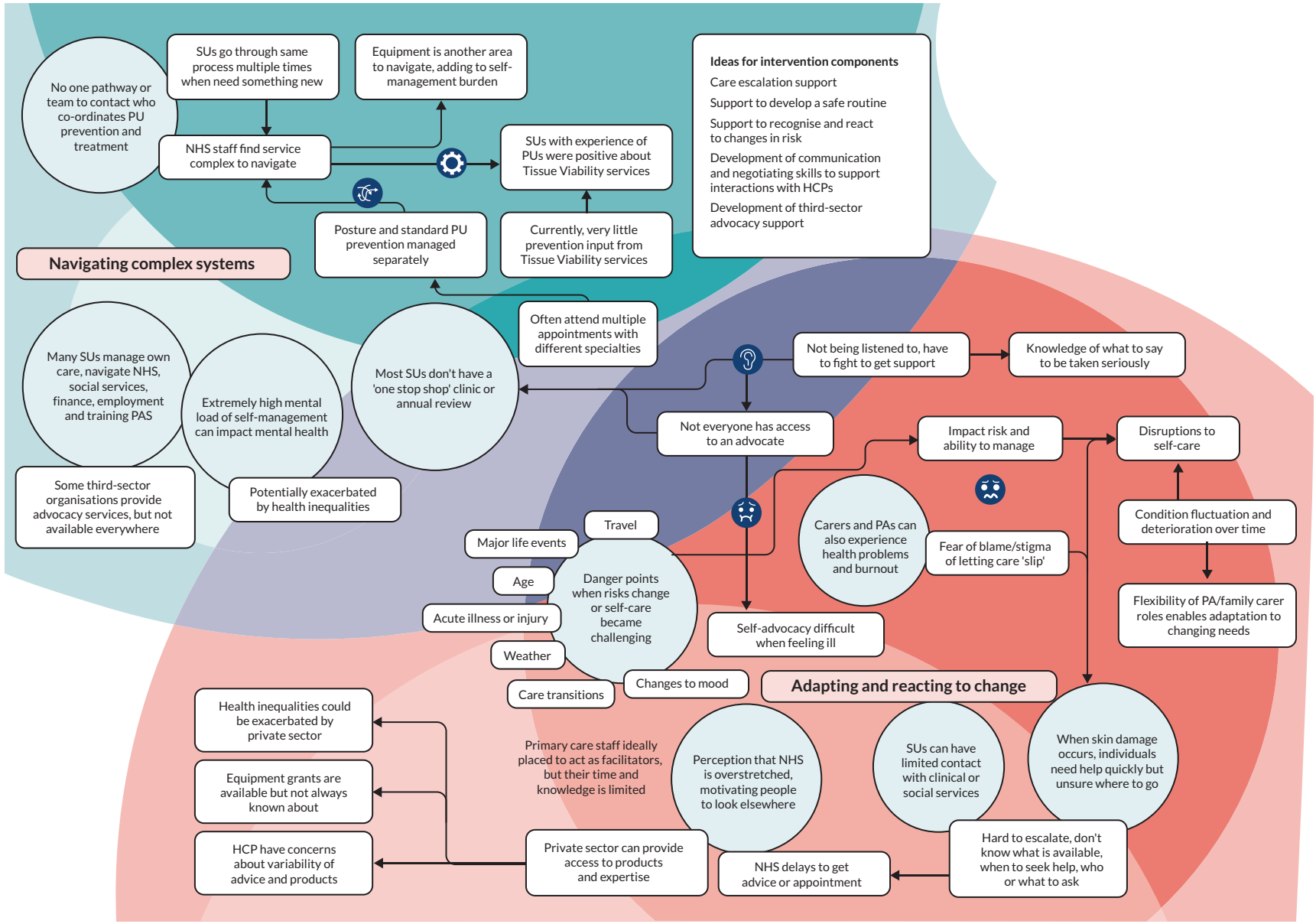

FIGURE 7 Navigating complex systems and adapting and reacting to change. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

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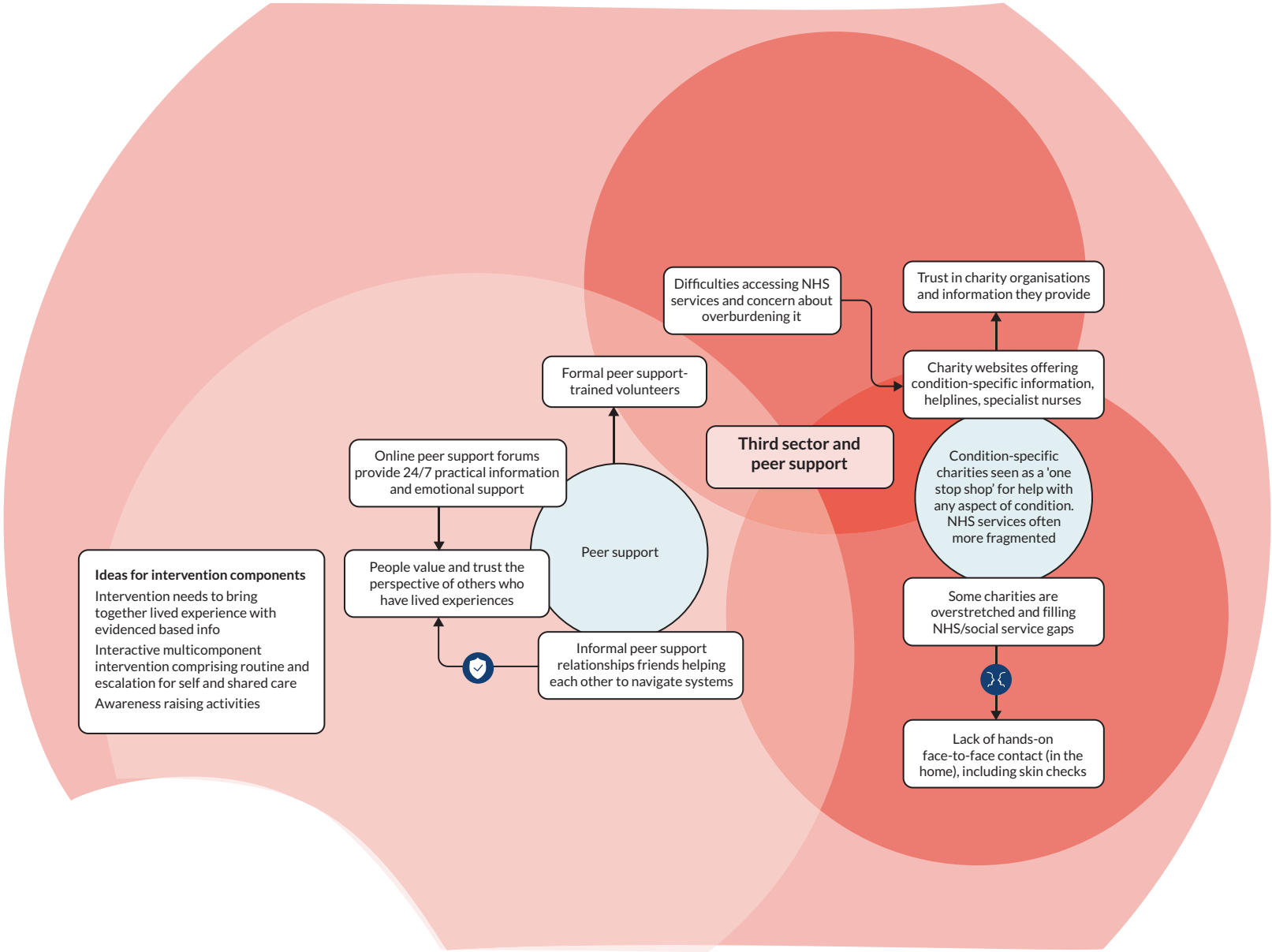

FIGURE 8 Third sector and peer support. This figure is reproduced from Muir *et al.*[1] This is an open access article distributed in accordance with the Creative Commons Attribution 4.0 (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/. This figure includes minor additions and formatting changes to the original text.

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