

# Exploring the use of images to support short break conversations with unpaid carers

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# Quality in Ageing and Older

# Exploring the use of images to support short break conversations with unpaid carers

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#### Exploring the use of images to support short break conversations with unpaid carers

#### **Abstract**

Purpose: Short breaks enable unpaid carers to have a life alongside caring, supporting their physical and emotional wellbeing. In the United Kingdom, short breaks are usually explored during a Carers Assessment. The conversations underpinning these assessments require considerable skill and presently there are few tools to support the exploration of short break needs, desired outcomes, and options. Images are used in other conversations to enhance communication, help people consider options and broaden thinking. We explored whether and how stakeholders thought images might support short break conversations.

Approach: To improve access to meaningful short breaks, we need to be guided by the insights of unpaid carers, those they support, practitioners, commissioners, and policy makers. We hosted two online involvement events, designed to facilitate the exchange of perspectives and ideas amongst diverse stakeholders. The events explored the acceptability, facilitators, and challenges of using images to enhance unpaid carer short break conversations.

Findings: The online events were attended by 47 short break stakeholders. These stakeholders saw merit in using images to support short break conversations. They identified several facilitators and challenges to introducing images into practice. The paper highlights how this learning can inform future research and practice development.

Originality: Supporting the wellbeing of older unpaid carers is a pertinent concern as the number of older unpaid carers continues to grow. This paper reports on how stakeholders have informed the earliest stages of practice and research development in a relevant area and provides a model of involvement that others can emulate.

#### **Key words**

Carers Assessment, Respite Care, Outcome Focused Conversations, Unpaid Carers, Short Breaks, Short Break Needs, Short Break Outcomes, Public Patient Involvement

#### Introduction

During the COVID-19 pandemic more than 4 million people in the United Kingdom (UK) aged over 65 were providing unpaid care (Age UK, 2021). Wales (the location of this work) has the highest proportion of older unpaid carers (Social Care Institute for Excellence, 2018), making support for unpaid carers a key area for research, policy, and practice development. Engaging with stakeholders at the earliest stages of research is fundamental (National Institute for Health Research (NIHR), 2019). Practice development is best co-produced with people with lived experience (Welsh Government, 2014). The work we report has actioned these principles to inform research and practice development to enhance unpaid carer short break conversations.

# The practice development and research area

Unpaid carers support friends or family members who need support due to illness, disability, a mental health problem or an addiction [Redacted]. Providing unpaid care can result in negative mental and physical health impacts (Farina *et al.*, 2017) and preventative interventions, such as short breaks, can make a positive difference to unpaid carer wellbeing (Vandepitte *et al.*, 2019). Short breaks are any form of service or assistance that enable unpaid carers to have sufficient, regular periods away from their caring responsibilities with

the purpose of supporting the caring relationship and promoting the wellbeing of the person with support needs, the unpaid carer and other impacted family members (Shared Care Scotland, 2017).

In the UK, short break needs are explored during Carers Assessments (CAs). Optimally, CAs develop partnership working, joint understanding (Hanson *et al.*, 2008) and establish the foundations for personalised support (Scottish Government, 2016; Welsh Government, 2021). Unpaid carers can face challenges engaging in these conversations:

- Needing 'permission' to think through their own outcomes and quality of life
- Feeling unprepared
- Knowing little about possible options
- Finding it difficult to think about 'what matters to them' due to their intense caring situation [Redacted]

For older unpaid carers cognitive, sensory and communication challenges may also impede these conversations. Practitioners can be challenged due to:

- Limited time (Hanson *et al.*, 2008)
- Limited knowledge about short break options
- Fear of raising unpaid carers' expectations [Redacted]

These challenges impact on unpaid carers experience of support and many unpaid carers feel that their short break needs are not sufficiently explored during CAs (Carers UK, 2019).

In other assessments exploring emotive and complex subjects, images provide a conversation scaffold and aid communication, supplementing the verbal exchange. For instance, images can support decision-making about breast cancer surgery (Yen *et al.*, 2020) and are used with people who might find it challenging to articulate their desired outcomes (Stans *et al.*, 2019). Images have been used to communicate prognostic information to older adults and their unpaid carers (Maxwell *et al.*, 2020) and to help older adults living with cognitive impairment share their experiences (Phillipson *et al.*, 2019). Despite these recognised benefits of using images the authors identified no research exploring how images may support short break conversations.

Images to support unpaid carer short break conversations could help implement policy ambitions, as described in:

- Care (England) Act (Department of Health, 2014)
- Social Services and Wellbeing (Wales) Act (Welsh Government, 2014)
- Carers (Scotland) Act (Scottish Government, 2016)
- Carers and Direct Payments Act (Northern Ireland) (Northern Ireland Assembly, 2002)

Similar policy ambitions are evident in other countries, for example, the Lifespan Respite Care Reauthorisation Act, 2019 (USA: Congress, 2019) and the Social Services Act, 2010 (Sweden: International Labour Organisation, 2021).

#### The data collection events

Mindful of the National Standards for Public Involvement in Research (NIHR, 2019) and the need to co-produce practice development, we sought the views of stakeholders before planning how to develop and research the use of images further.

#### Aim and objectives

Our aim was to explore stakeholder perceptions of the benefits, facilitators, and challenges of using images to support short break conversations with unpaid carers.

The objective was to hold two online involvement events incorporating:

- Experiential exercises, offering opportunities to experience short break conversations *without* and then *with* images
- Discussions exchanging ideas about benefits, implementation challenges and solutions

#### Method

The project received ethical approval from [Redacted].

The events used a #Social Care Innovation Lab (#SCIL) approach. #SCILs originated in the Centre for Ageing and Dementia Research (CADR) and are co-supported by the Developing Evidence Enriched Practice (DEEP) programme. #SCILs bring people with different experience together to identify and take forward research and practice development ideas. The principles underpinning #SCILs are:

- Involvement: enabling meaningful connections and discussions
- Innovating: creating a safe space to explore ideas
- Improving: generating evidence [Redacted].

We held two online #SCILs using the Zoom meeting platform and mindful of the Active Offer in Wales (Welsh Government, 2018) Welsh speaking breakout rooms were offered. At the start of each #SCIL we reminded attendees of the need for confidentiality (not sharing discussions outside of the event). We highlighted that attendees should only share information they were comfortable disclosing. The events are summarised below, and the #SCIL outlines are in appendix 1.

#### #SCIL One

#SCIL One involved unpaid carers and practitioners. We shared information about the event with colleagues who cascaded this through their UK networks. When people emailed to register, we collected demographic details and people provided consent for the data to be used in publications, research, and practice development work.

We pre-assigned stakeholders to the breakout rooms ensuring that each contained a facilitator and people who could contribute experience as an unpaid carer, as a practitioner or as a practitioner with unpaid caring responsibilities. Stakeholders returned to the same room for each exercise, promoting an ongoing dialogue that developed shared understandings. The initial breakout exercise provided stakeholders with the opportunity to discuss short break needs, desired outcomes, and options *without* images. Stakeholders reflected on these conversations with the larger group, before returning to the breakout room for a further conversation where the facilitator *shared* images depicting short break outcomes and options. After an opportunity for further reflection, the potential benefits, and challenges of using images in practice were explored in a plenary.

#### #SCIL Two

#SCIL Two was attended by strategic staff, including commissioners, policymakers, and researchers. Recruitment processes were like #SCIL One, although more invites were addressed to identified individuals. No stakeholders at #SCIL One had come from England or Northern Ireland, so we limited recruitment to Wales and Scotland to ensure people had experience of similar policy contexts. Stakeholders were pre-assigned to breakout rooms to ensure a mix of attendee roles and people remained in the same breakout room throughout.

Stakeholders took part in an experiential exercise to see *if* and *how* images supported their short break thinking. Discussions focused on how the use of images could be implemented and evaluated in practice.

#### Data analysis

#SCILs were audio-recorded, and the recordings saved on the [redacted] secure network. Attendee contributions were transcribed to evidence learning points through peoples' own words. [Redacted] analysed the transcripts following a thematic approach aligned to the reflexive thematic analysis approach described by Braun and Clarke (2019). The steps involved:

- Immersion in the data
- Identifying codes: a deductive and inductive process
- Grouping codes into the pre-determined themes and creating additional themes that told a story about the inductively generated codes
- Reviewing themes to ensure a convincing account
- Defining and naming themes to capture their essence
- Writing a narrative of the analysis findings

The analysis approach is best described as codebook thematic analysis under the tripartite typology outlined by Braun and Clarke. The codes were primarily derived deductively from the questions we set out to answer. Although coding was undertaken by a single researcher, the codes grouped under the themes and sub-themes were sense-checked by other authors.

Through immersion in the data during the coding process, [redacted] saw the potential to create an inductive theme around thinking of images as catalysts. Reflexively drawing on their wider understandings of unpaid care and short breaks informed the creation of this catalysts theme as a story about how images could support short break conversations.

#### **Findings**

Sample characteristics

Table 1 describes stakeholder characteristics. Notably, some stakeholders were 65 years and over and many indicated they had multiple types of experience to contribute. For instance, several practitioners said they had personal caring experience. People categorising themselves as 'other role' included a Carer Support and Development Officer and a Social Prescribing Coordinator.

#### [Table 1]

#### Thematic analysis

The data presented reflects stakeholder's reflections after they had experienced the use of images. There were no notable differences between stakeholder groups in their reactions to or reflections on the use of images. However, strategic stakeholders reflected more on points related to evaluation. We identified several sub-themes that related to the a-priori themes (e.g., facilitators, challenges) and lab discussion points (how to capture the difference that images make) as outlined in Figure 1 and our narrative based on the figure below:

### [Figure 1]

Images: a catalyst for thinking and talking together

Stakeholders agreed there was merit in using images to support unpaid carer short break conversations and that images would help explore what a 'good outcome' could look like:

I think they could be used regarding outcomes if the carer or the user of services didn't know what good looked like (Unpaid carer/practitioner)

This could be a catalyst for deeper and broader conversations.

#### Deepening the conversation

Stakeholders thought images could make short break conversations meaningful, and thought-provoking:

...what really struck me from the first time we looked at the pictures was how, how quickly our conversation moved from professional almost discussion to a meaningful thought-provoking discussion so I think that the pictures can be really useful in terms of getting down to thoughts, feelings, thinking... (Unpaid carer/ practitioner)

Images helped capture and address unpaid carer emotions associated with short breaks, such as, guilt and anxiety:

... they're really good to help describe emotions, so where people sometimes don't really want to say how they're feeling or they're feeling embarrassed about how they're feeling, or they just can't describe it and I think sometimes that's easier to do in pictures than in words... (Unpaid carer/practitioner)

The 'deepening' effect of images on conversations, as identified by stakeholders, could help unpaid carers exercise voice and control. This is a policy principle underpinning support for unpaid carers (Welsh Government, 2014; Scottish Government, 2016). A 'deepening' in the conversation could build trust between practitioners, which may moderate the power inbalance in the CA process:

You shift that power balance then don't you, we become on equal ground so that the person doesn't feel, well I think they'd have a more honest conversation with you... (Unpaid carer/practitioner)

This could mitigate against unpaid carers feeling that their ability to care is being scrutinized and further enhance trust in the assessment and support planning processes:

...deflects from the person feeling scrutinized (Unpaid carer/ practitioner)

#### Broadening the conversation

Stakeholders noted it can be difficult to define what a short break and its outcomes might look like. Images could help articulate this and help unpaid carers think beyond their caring role:

...they no longer see themselves as an individual, so it's really hard to tap into those things that they enjoyed prior to this overwhelming role, and I think the images would really help with that (Strategic staff)

Stakeholders also suggested images could challenge assumptions about short breaks needs, preferences and desired outcomes. They thought this might help unpaid carers think more expansively about how to use their break time and legitimise their short break preferences:

...sitting on my sofa staring at the wall with my mouth open because I never get to do that, that's ok, you know, we need to give ourselves a bit of permission maybe or as practitioners think oh if that's what they want to do fine (Unpaid carer/practitioner)

There was a rich discussion related to this sub-theme about the right time to use images. Some thought images could be introduced at the beginning of the short break conversation as an icebreaker. Others felt they could be introduced towards the end of the CA once a trusting relationship was established:

... there needs to be a bit of a relationship first before you plant pictures in front of somebody and expect them to open up (Strategic staff)

Some stakeholders believed a phased approach might be ideal, leaving images with the unpaid carer so they had time to reflect on them and then following up with further conversations. Stakeholders noted that the use of images need not be confined to conversations that plan short breaks. They saw images supporting conversations once a break had taken place to capture in a broader way the carer's experience, understand outcomes and plan future breaks:

... especially if someone can't express very well how a break went, it might be easier for them to just identify an image as to how they felt during their break (Strategic staff)

Such an approach could capture richer insights to inform short break policy development and commissioning:

...images could help insert the emotion into policy... images bring to life, they are very direct and they could be a really important and rich tool to inform policy-making ..., so it would help us to understand more clearly the quality of somebody's break experience and to use that information to support future policy making and service development (Strategic staff)

#### **Facilitators**

The sub-themes of choice, sensitivity to time and context, explanation and varied images have been woven into a single narrative as the facilitators were not presented as 'stand-alone' elements. Stakeholders believed unpaid carers should have a choice about whether to use images:

...there'd need to be an explanation as to the rationale for using them and obviously a choice cos you couldn't just thrust it upon carers if they weren't interested (Unpaid carer/practitioner)

They saw value in developing a universal image set that included scope for personalisation:

...having a standard set of pictures and the associated things that are actually reflected in the pictures as a resource so then everybody in Wales is using this bank of resources and I appreciate people can put in individualised their own personal pictures... (Unpaid carer/practitioner)

Personalisation could include the option for unpaid carers to add their own images:

Carers might want their own images, that might mean more to them than anything that we could ever show them... (Strategic staff)

Flexibility was key. Stakeholders said unpaid carers should be supported to work with images on their own terms. Images will not resonate for every unpaid carer. Some may find them unnecessary or demeaning, especially if they can clearly articulate their short break needs:

...if someone was quite articulate in what they wanted and very clear and you start showing them some pictures they might think that might be a bit patronising (Strategic staff)

A universal image set would promote equity. Stakeholders thought providers should offer unpaid carers various images depicting a range of short breaks:

...they might be health and beauty, they might be care providers, they might be sports or leisure facilities ... to supply a couple of images of what they've done, what's worked for them, variety, so that we're slowly building up our image bank of possibilities (Strategic staff)

However, practitioners will need support to embed and use a universal image set:

So, it's what support do we need to give practitioners to help them even think about using cards and what sort of training might be useful (Strategic staff)

Stakeholders recommended helping practitioners to recognise that short breaks mean different things to unpaid carers. Practitioners might also need to do preparatory work before introducing images:

You don't whip them out like a McDonald's menu... (Strategic staff)

Especially as deepening the conversation may trigger difficult emotions:

...it makes that link between your memories, your identity, and your sense of self, which can be really positive for a lot of individuals, but also can be quite triggering (Strategic staff)

The importance of practitioners providing well-timed, supportive, safe spaces was highlighted:

...when I'm not in a good place and I'm responding to my situation maybe on a visceral level and somebody came with a load of pictures they would probably not get a good response from me in that moment (Unpaid carer/ practitioner)

#### Challenges

As with facilitators the sub-themes identified under challenges (managing carer expectations, practitioner skill, time requirements and strategic level support) were discussed as coexisting factors. Although there was recognition that aspirational images might benefit unpaid carers with the means to fund their short breaks, stakeholders had reservations that some images (or

how some unpaid carers interpreted them) might unfairly raise unpaid carer short break expectations. Hence, careful image selection was important:

...are you showing me these because these are what should be on offer to me, or are you showing me these to give me ideas of what I could be implementing in my own life... (Unpaid carer/practitioner)

...it's not good having a picture of a lovely spot in the Maldives if there's no way of getting there (Strategic staff)

Recommendations included ensuring that images did not make assumptions about how unpaid carers 'should' spend their short break time and selecting images to reflect the diversity of the unpaid carer population and caring relationships. Stakeholders agreed that practitioner skill was important in managing unpaid carer expectations:

... make sure whoever was using them as the practitioner was skilled in using it... (Unpaid carer/ practitioner)

This related to the perception that practitioners must work in emotionally intelligent ways with images:

if you're going to bring in a tool, just got to be careful that it's helpful to the conversation and not get in the way of it, not get in the way of the listening (Strategic staff)

They suggested providing practitioners with opportunities to practice using the image set for themselves to develop empathy and an understanding of what does and does not work.

Stakeholders expressed some uncertainty about the time requirements for using images. The use of images may lead to longer short break conversations:

I think cos people need to think about the pictures and what, you know, and that could make the conversation take much longer, which might be a limiting factor for practitioners and for carers... (Unpaid carer/practitioner)

Although images may speed up CAs if engagement is enhanced:

...having the pictures will speed up the conversation, because you'll get to the outcomes quicker, because it will spark something within the person... (Strategic staff)

Given the potential time requirements and the need to embed new practice, stakeholders were agreed that the use of images needed further co-development with unpaid carers, people with support needs, practitioners, and strategic staff:

You'd need the support of the organisation wouldn't you... (Unpaid carer/practitioner)

#### Capturing the difference

Stakeholders agreed it was important to capture if images made a difference. They were keen to capture whether images impact on unpaid carer engagement with the short break conversation:

... having short breaks conversations without images and then having short breaks conversations with images and teasing out the difference that that made. How the conversations went and how that impacted on the carer and practitioner relationship (Strategic staff)

Strategic staff stressed that evaluation methods must have minimal burden. They suggested practitioners could sense check with unpaid carers whether images were helpful and capture 'in the moment' impact:

... some of the most immediate impact of using images might just be in the quality of the conversation, the rapport, the feeling in the room ... those, kind of, in the moment small changes that is just enriching something (Strategic staff)

Strategic staff agreed that tracking short break decisions made when images *are* used and when images *are not* used was important:

...evidence for commissioning and policy development is taken from statistics of carers that appear on our systems, and whether there's a way of just being able to note whether an image format was used or not... and images were used in the story and the assessment, or not... (Strategic staff)

#### **Discussion**

This work implemented the National Standards for Public Involvement in Research (NIHR, 2019). Insights have identified areas where research and practice can be developed, underlining the importance of involving stakeholders in the earliest stages of these activities. Short breaks are an important area for research and practice development. Short breaks support the wellbeing of unpaid carers and current CA formats do not provide optimal help to unpaid carers who might struggle to identify and communicate their short break needs, preferences, and desired outcomes. Using images could be a valuable to the CA process.

#### Key findings

Stakeholders saw value in using images to support unpaid carer short break conversations. Images were seen to have the potential to deepen and broaden conversations.

The wider literature exploring images to support different types of conversation often focuses on images as a scaffolding tool. This relates to the concept of 'deepening' as it embodies the idea of images supplementing the verbal exchange and helping people share their experiences (e.g., Phillipson *et al.*, 2019). Unpaid carers can express their feelings and hopes honestly, and a better understanding develops between unpaid carers and practitioners (Hanson *et al.*, 2008). The literature suggests that images can encourage unpaid carers to share unspoken ideas, experiences, and feelings (Levy *et al.*, 2020). The idea of 'broadening' or using images to expand thinking is less of a focus in the existing literature. The use of images to 'broaden' conversations is an interesting area of exploration as it is a different facet of using images to support communication.

Many of the identified facilitators to using images relate to the personalisation agenda in social care (Scottish Government, 2016; Welsh Government, 2021) and resonate with strengths-based approaches (Rapp and Chamberlain, 1985). These facilitators help implement person-centred care and stakeholders agreed this could be one way of implementing the

principles of voice and control endorsed in UK legislation (e.g., Welsh Government, 2014). Voice and control are enhanced through ensuring unpaid carers receive a rationale for using images and are supported to choose whether they wish to use them. Personalised support is an important factor in achieving personal outcomes in a variety of contexts (Parley, 2001) and in the context of short break conversations these facilitators would 'make real' the 'optimal' CA process that builds partnerships and joint understanding (Hanson *et al.*, 2008). Research identifies that personalised information and two-way conversation is an area of the CA process in need of practice development (Samsi *et al.*, 2023).

Several of the challenges identified (i.e., the need for strategic support, time requirements and practitioner skill) are common concerns in social care and are not specific to the use of images [Redacted]. Rather these challenges will impact on the successful adoption of any new resource. Concerns about managing unpaid carer expectations are more specific to images and the short break conversation. Similar concerns have been expressed in previous research (Hanson *et al.*, 2008). As discussed in [Redacted] contrary to the concerns expressed by #SCIL attendees, the research suggests that when open conversations are facilitated, modest support needs are identified. Conversely, closing-down conversations to avoid raising expectations can inadvertently result in oppression. Future practice development activities need to elucidate how to ensure that images can broaden conversations whilst remaining acceptable to practitioners and strategic stakeholders.

The learning from the events suggests that the Exchange model of assessment (Smale *et al.*, 1993) is a useful model to base future work in this area. In this model the idea is to facilitate an exchange (or two-way flow of information) in which power is shared. It is a model that aims to shift the focus of conversations from deficits to strengths. It talks to the facilitators (and acknowledges the challenges) identified by #SCIL attendees. It provides a model in which images could be used to both deepen and broaden conversations.

#### Strengths and limitations

Involving stakeholders at the start of research and practice development helps ensure that projects reflect their priorities and deliver positive impact (Frogatt *et al.*, 2015). A criticism of involvement is that researchers and practice developers often listen to the same voices (Eccles *et al.*, 2018). Through the #SCIL method we heard multiple stakeholder voices as the events were well attended. The time-limited nature of the events might have had broader appeal and made involvement feasible. Holding online events allowed us to bring together stakeholders from Wales and Scotland and supported the involvement of unpaid carers, who can find it difficult to attend in-person events due to their caring responsibilities. Stakeholders unable to access online meetings were excluded and despite repeated efforts no stakeholders from England or Northern Ireland attended. We cannot ascertain why some stakeholders chose not to participate.

Although the sub-themes identified resonate with the existing wider literature, the self-selecting nature of the attendees means that caution is needed if generalising or transferring the learning. We acknowledge that the analysis would have been strengthened if we had asked attendees to sense check our findings. A method of transcription that enabled us to identify which quotes were made by which attendees would have facilitated a more detailed investigation of between or within group differences. We acknowledge that the voice of people with support needs is currently missing from this exploration, and this will be a key voice to be reflected in future work.

Implications for policy and practice

These involvement events were an initial attempt to explore the co-produced use of images to support unpaid carer short break conversations. They demonstrate that stakeholders are interested in this idea and willing to work with academics to develop this area of practice. This suggests this is a fruitful area for research and practice development. We are planning research that co-productively takes this work forward.

The learning points can inform the implementation of current policy and practice speaking to the importance of ongoing endeavours to strive for person-centred care and strengths-based support. The learning concerning the importance of broadening conversations speaks to the need for creative and flexible approaches. One practical step to institute positive change in the current system might be to explore ways to upscale the use of the Exchange model of assessment (Smale *et al.*, 1993) in the CA process.

#### Conclusion

The involvement events helped us understand how stakeholders perceive the use of images to support unpaid carer short break conversations. They identified that images could both deepen and broaden short break conversations and detailed numerous facilitators and challenges to using images in practice. The events evidenced an appetite to explore this area of practice and the learning will inform future research and practice development. If coproduced research confirms that images support unpaid carer short break conversations, there will be learning that is transferable to other assessment and support contexts.

#### References

Redacted references:

Redacted, 2023 (In Press)

Redacted, (2021a)

Redacted (2021b)

Redacted (2019)

Redacted (2015)

Age UK. (2021), "New age UK research finds the numbers of UK over age 65s caring unpaid nearly double during the pandemic to more than 4 million", available at: <a href="https://www.ageuk.org.uk/latest-press/articles/2021/new-age-uk-research-finds-the-numbers-of-uk-over-65s-caring-unpaid-nearly-double-during-the-pandemic-to-more-than-4-million/">https://www.ageuk.org.uk/latest-press/articles/2021/new-age-uk-research-finds-the-numbers-of-uk-over-65s-caring-unpaid-nearly-double-during-the-pandemic-to-more-than-4-million/</a> (accessed 16 Aug 2022).

Braun, V., and Clarke, V. (2019), "Reflecting on reflexive thematic analysis", Qualitative Research in Sport, Exercise and Health, Vo. 11, No. 4, pp. 589-597. doi: 10.1080/2159676X.2019.1628806

Carers UK. (2019), "State of Caring. A snapshot of unpaid care in the UK", Carers UK, UK.

Congress. (2019), "Lifespan Respite Care Program Reauthorization Act of 2019", available at: <a href="https://www.congress.gov/bill/116th-congress/senate-bill/995/text">https://www.congress.gov/bill/116th-congress/senate-bill/995/text</a> (accessed 10 April 2022).

Department of Health. (2014), "Care Act 2014", Department of Health, UK.

Eccles, A., Bryce, C., Turk, A. and Atherton, H. (2018), "Patient and public involvement mobile workshops- convenient involvement for the un-usual suspects", *Public Involvement and Engagement*, Vol. 4, p. 38. doi: 10.1186/s40900-018-0123-1

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingstone, G., Knapp, M., Murray, J., and Banerjee, S. (2017), "Factors associated with the quality of life of family carers of people with dementia: a systematic review", *Alzheimer's and Dementia*, Vol. 13 No. 5, pp. 572-581. doi: 10.1016/j.jalz.2016.12.010

Froggatt, K., Goodman, C., Morbey, H., Davies, S. L., Masey, H., Dickinson, A., Martin, W., and Victor, C. (2015), "Public involvement in research within care homes: benefits and challenges in the approach study", *Health Expectations*, Vol. 19, pp. 1336-1345. doi: 10.1111/hex.12431

Hanson, E., Magnusson, L., and Nolan, J. (2008), "Swedish experiences of a negotiated approach to carer assessment: the carers outcome agreement tool", *Journal of Research in Nursing*, Vol. 13, pp. 391-407. doi: 10.1177/1744987108095161

International Labour Organisation. (2001), "Social Services Act", available at: https://www.ilo.org/dyn/natlex/natlex4.detail?p isn=60673 (accessed 05 April 2022)

Levy, K., Grant, P. C., Tenzek, K. E., Depner, R. M., Pailler, M. E., and Beaupin, L. K. (2020), "The experience of paediatric palliative caregiving: a qualitative analysis from the photographs of meaning program", *American Journal of Hospice & Palliative Medicine*, Vol. 37 No. 5, pp. 364-370. doi: 10.1177/1049909119879413

Maxwell, C. A., Mixon, A. S., Conner, E., and Phillippi, J. C. (2020), "Receptivity of hospitalized older adults and family caregivers to prognostic information about acing, injury and frailty: a qualitative study", *International Journal of Nursing Studies*, Vol. 109. doi: 10.1016/j.ijnurstu.2020.103602

National Institute for Health Research. (2019), "UK standards for public involvement. Better public involvement for better health and social care research", NIHR, UK.

Northern Ireland Assembly. (2002), "Carers and direct payments act (Northern Ireland) 2002", Northern Ireland Assembly, UK.

Parley, F. F. (2001), "Person-centred outcomes. Are outcomes improved where a person-centred care model is used?", *Journal of Learning Disabilities*, Vol. 5 No. 4, pp. 299-308. doi: 10.1177/146900470100500402

Phillipson, L., Smith, L., Caiels, J., Towers, A-M., and Jenkins, S. (2019), "A cohesive research approach to assess care-related quality of life: lessons learned from adapting an easy

read survey with older service users with cognitive impairment", *International Journal of Qualitative Methods*, Vol. 18, pp. 1-13. doi: 10.1177/1609406919854961

Rapp C. A., and Chamberlain, R. (1985), "Case management services for the chronically mentally ill", *Social Work*, Vol. 30, pp. 417-422. doi: 10.1093/SW/30.5.417

Samsi, K., Orellana, K., Cole, L., and Manthorpe, J. (2023), "Understanding factors influencing residential respite service use by carers of people living with dementia using Andersen's behavioural model of health services use: a qualitative study", *Aging & Mental Health*, online. doi: 10.1080/13607863.2023.2196254

Scottish Government. (2016), "Carers (Scotland) act 2016", Scottish Government, UK.

Shared Care Scotland. (2017), "Short breaks definition", available at: <a href="https://www.sharedcarescotland.org.uk/resources/briefings/short-breaks-definition/">https://www.sharedcarescotland.org.uk/resources/briefings/short-breaks-definition/</a> (accessed 01 January 2022).

Social Care Institute for Excellence. (2018), "Preventative Support for Adult Carers in Wales: Rapid Review", SCIE, UK.

Smale, G., Tilson, G., Biehal, N., and Mars, P. (1993), "Empowerment, assessment, care management and the skilled worker", National institute for Social Work Practice and Development Exchange, UK.

Stans, S. E. A., Dalemans, R. J. P., de Witte, L. P., and Beurskens, A. J. H. M. (2019), "Using talking mats to support conversations with communication vulnerable people: a scoping review", *Technology and Disability*, Vol. 30, no. 4, pp. 153-176. doi: 10.3233/tad-180219

Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., and Annemans, L. (2019), "Effectiveness of an in-home respite care program to support informal dementia caregivers: a comparative study", *International Journal of Geriatric Psychiatry*, Vol. 34 No. 10, pp. 1534-1544. doi: 10.1002/gps.5164

Welsh Government. (2014), "Social services and well-being (Wales) Act 2014", WG, UK.

Welsh Government. (2018), "The Welsh Government standards (no. 7) regulations 2018", WG, UK.

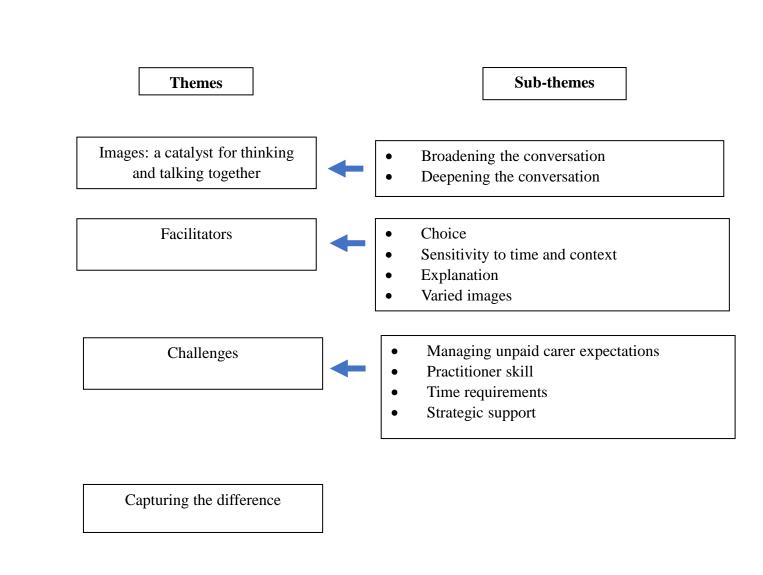
Welsh Government. (2021), "Strategy for unpaid carers: delivery plan 2021", WG, UK.

Yen, R. A., Durand, M-A., Harris, C., Cohen, S., Ward, A., O'Malley, A. J., Schubbe, D., Saunders, C. H., and Elwyn, G. (2020), "Text-only and picture conversations aids both supported shared decision making for breast cancer surgery: analysis from a cluster randomized trial", *Patient Education and Counseling*, Vol. 103, pp. 2235-2243. doi: 10.1016/j.pec.2020.07.015

Table 1: Characteristics of people attending the labs

	Lab 1	Lab 2
Number of attendees		3 Commissioners
		4 Policy leads
	7 People identifying as	
	both a practitioner and	2 Researchers
	an unpaid carer	9 Other
Gender C	1 Male	2 Males
	18 Females	25 Females
		1 Not state
Average age (range)	53 years (30-67 years)	46 years (23-64 years)
Average number of	20 years (6-43 years)	Not asked
years in practice/ of		
managerial, policy		
commissioning		
experience (range)		
	Not asked	6 years (0-20 years)
years working in		
policy,		
commissioning and/		
or management		
(range)		
Average number of	15 years (3-45 years)	Not asked
years caring (range)		
	2 (1-3)	Not asked
people cared for		
(range)		
<u> </u>		

Page 15 of 17 Figure 1: Lab themes and sub-themes Quality in Ageing and Older Adults



# **Supplemental Material - #SCIL outlines**

Outlines of the two #SCILs are provided below.

# **#SCIL 1 outline**

Time	Content	
allocation		
2 minutes	Welcome and housekeeping	
8 minutes	A PowerPoint presentation to set the scene	
5 minutes	Ice breaker polls:	
(	• Who has had experience of taking part in short break conversations?	
	If answered Yes to poll 1: Were you the person asking, 'what	
	matters?' or the person answering?	
	How much experience do you have of meaningful conversations	
	around support provision?	
15 minutes	Breakout room exercise 1	
	A group conversation about:	
	What types of short break are you or the people you work with	
	interested in?	
	What would be meaningful short break outcomes for you or the	
	people you work with?	
5 minutes	Feedback opportunity in the main session	
15 minutes	Breakout room exercise 2	
_	The same conversation as in exercise 1, but pictures prompts are provided	
5 minutes	Feedback opportunity in the main session	
10 minutes	Comfort break	
20 minutes	Breakout room exercise 3	
	A discussion about using pictures in practice:	
	What would be the challenges?	
	What would be the facilitators?	
	How could you capture if it was making a difference?	
20 minutes	Feedback and then discussion in the main session	
10 minutes	Thank you and next steps	
	Short questionnaire completed	

# **#SCIL 2 outline**

Time	Content
allocation	
2 minutes	Welcome and housekeeping
8 minutes	Ice breaker polls:
	Your working role?
0)	<ul> <li>Is using pictures to support outcome conversations something you have considered before?</li> </ul>
	• If yes to poll 2: what service/ area were you working in when this was considered?
10 minutes	Presentation setting the scene including an individual experiential exercise
20 minutes	Breakout room exercise 1
	Each room considered a particular challenge with implementing pictures in practice and explore potential solutions. The challenges discussed were:
	Room 1: Staff training/ support needs
	Room 2: Timing – when to use, how to accommodate any additional time
	demands
	Room 3: Supporting and managing carer expectation
	Room 4: Ensuring equitable provision
	Room 5: Sustaining the initiative
20 minutes	Feedback to the main session
10 minutes	Comfort break
5 minutes	Opportunity to share initial reflections on ideas shared
20 minutes	Breakout room exercise 2
	Two questions discussed:
	How could information gained through pictures feed into better
	decision making (be that commissioning or policy development)?
	How could we evaluate the impact of using pictures on the
	conversation and on carer outcomes?
10 minutes	Feedback to main session and discussion
15 minutes	Thank you and next steps
	Opportunity to ask questions
	Short questionnaire completed