Care Choices

Prototyping Report

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DWP Human-Centred Design Science and policy leads

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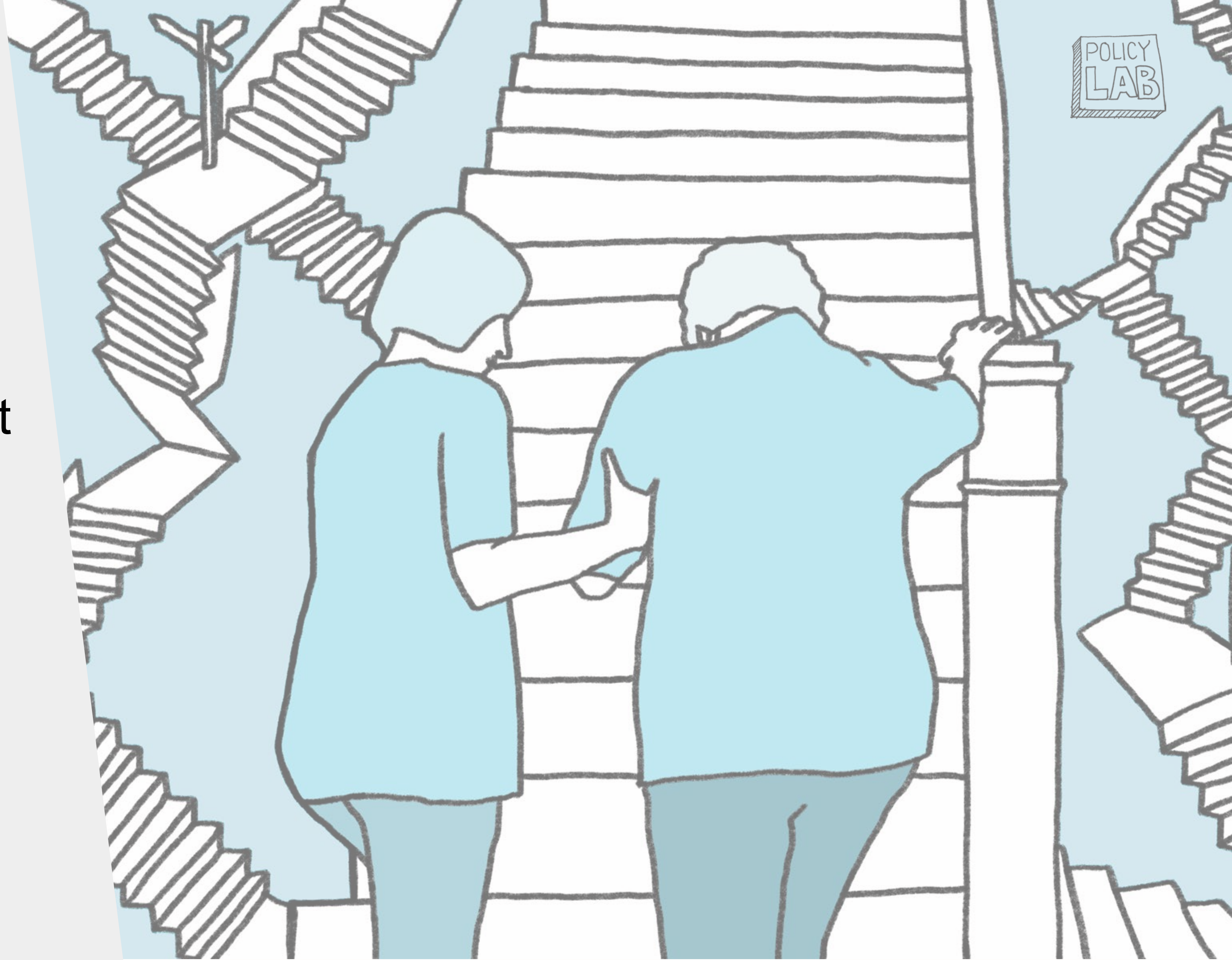

This is the prototyping report for the collaboration between the Department for Work and Pensions (DWP) and Policy Lab on the Care Choices project that took place between December 2021 and March 2022.

We would like to thank the many stakeholders who were instrumental in developing, refining, and testing the prototypes in this report. In particular we would like to thank the many carers who participated, as well as Tower Hamlets Carers Centre and the Civil Service Carers Network.

This report provides a summary of key findings. It also introduces an overview of the prototypes, which were developed and tested as part of the project.

While the insights contained were gathered in 2022, they may still prove useful to those developing information for carers. The context of caring, carers' information needs, and the fuller scope of possible solutions available today should be considered when reading the insights in this report.

Further outputs from other stages of the project, including a DWP-authored report '*Supporting working people to make informed decisions about work and care',* can be found on the following webpage: Carers' Employment Digital Discovery and Care Choices reports.

Policy Lab is a multidisciplinary team working openly and collaboratively across government, bringing expertise in policy, ethnography, systems thinking, futures, and design.

We support the public sector to achieve better policy outcomes by partnering on innovative projects, leading and demonstrating best practice, and delivering training.

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Policy Lab is a multi-award winning, and one of the world’s longest-standing government Labs dedicated to policy innovation.

Our projects test new approaches which bring lived experience and experimentation into policymaking. We share our new tools and techniques openly on our blog and the Open Policy Making Toolkit to encourage system-wide transformation.

Find out more about Policy Lab via the following link:
https://openpolicy.blog.gov.uk/

Executive Summary

The DWP partnered with Policy Lab to address the following challenge:

> ***How can we better enable working people to build knowledge and understanding needed to make timely, informed choices about their role in meeting an adult friend or relative's care needs?***

By taking a design approach, this project re-engaged a community of practice – a community of organisations and experts involved in providing information to carers. Co-design workshops and prototype testing led to the identification of four interventions responding to the above challenge. More on methodology can be found in Section 2.

The four interventions were:

1. **Awareness-raising campaigns** utilising touchpoints across the system, encouraging pro-active choices, and signposting people to relevant resources.
2. **Sharing real experiences** to help potential carers synthesise information and make decisions through multimedia channels like podcasts and supporting real human interaction where possible.
3. **Conversation support tools with concise and relevant advice.** This could be through physical materials like prompt cards or using digital technologies like targeted advertising or chatbots.
4. **Information navigation improvements** tailoring content for users on existing websites and better signposting from trusted sites.

Executive Summary (continued)

Prototypes (Section 4) for each of these interventions were developed in collaboration with the Social Design Institute, University of the Arts London. They were tested and iterated with carers and the Community of Practice. Section 4 contains detailed feedback on each prototype, including how they were iterated, what risks and opportunities were considered, and suggested actions for government to progress the ideas.

A set of design principles (Section 5) emerged which can be applied to other interventions for potential carers.

Policy Lab set out suggestions on how a community of practice (Section 6) comprising organisations and experts could play a vital role in the further development and delivery of these ideas.

Contents

1. Introduction

Background, methodology, and project challenges

Context

The Department for Work and Pensions (DWP), Department for Health and Social Care (DHSC), Department for Business and Trade (DBT) and Office for Equality and Opportunity (OEO) have undertaken extensive behavioural research which highlighted that, despite wanting to continue working, many carers reach a point where they feel employment is not compatible with caring.

The research also found that choices around care are often made hastily in response to urgent situations, and that information for carers is fragmented and inadequate, with information for 'potential carers' (i.e. working people making decisions about work and care) being particularly poor.

This work was conducted as part of the Care Choices project. To learn more about the broader project, the report 'Supporting working people to make informed choices about work and care' may be found on the following webpage: Carers' Employment Digital Discovery and Care Choices reports.

Challenge statement

The DWP wanted to understand more about how potential carers can be supported to navigate the, currently very fragmented, information landscape and convoluted choice architecture, as well as making the landscape easier to navigate through better signposting between sources.

Our challenge statement:

How can we better enable working people to build knowledge and understanding needed to make timely, informed choices about their role in meeting an adult friend or relative's care needs?

Focus on 'potential carers': those facing early decisions about work and the care needs of a friend or family member.

These individuals often do not identify with the language of 'care' and therefore struggle to unlock support and recognise options that are available to them.

Through an initial evidence discovery exercise and discussion, we built upon the notion of informed decision-making and also acknowledged sense-making as an important part of the decision-making process.

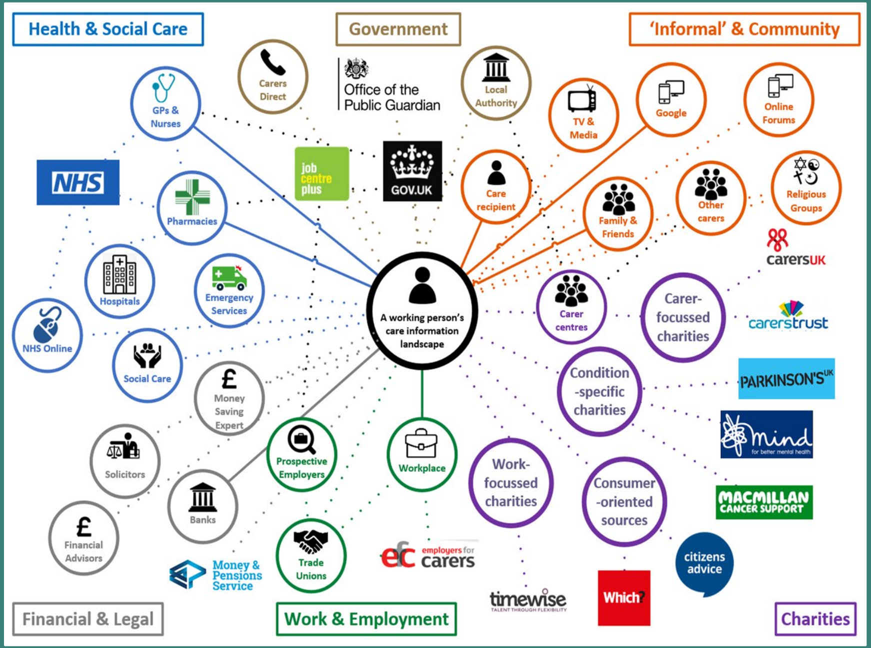
To make informed decisions, potential carers need to make sense of their own situation, the options available to them and the implications that would come with certain decisions.

Community of Practice

The significant number of stakeholders that provide services and resources to potential carers calls for a systemic approach to our challenge. Actors include those across central and local government, health and social care services, carer-focused and condition-specific charities, employers, and financial and legal services.

DWP had previously engaged a community of practice with the representatives of the different stakeholder groups to come together to better understand the challenge, the current ecosystem and what improvements could be made. When dealing with a complex and intersectional problem, collaboration is vital to enact meaningful change.

One of the aims for this project was to re-engage this community. Its involvement provided a wealth of knowledge and expertise. Through this project we also were able to co-create the working practices necessary for taking a systems-wide approach to the challenge going forward.



A working person's care information landscape

Desired outcomes

Short-term outcomes: indicators of informed decision-making

Potential carers:
Make more timely, informed choices about work and care

Have constructive conversations with family, the cared-for, & employers

Make active, early decisions using information about how to meet care needs

Consider their rights and entitlements, options and long-term implications

Know where to go to get information

Consider their own needs

Feel able to make an informed choice to adapt care when needed

Make decisions collectively with other potential carers

Have greater awareness of caring, its implications & the value of information

Intermediate Outcomes

More sustainable care arrangements

Fewer carers feel like they have no choice but to give up work to care

Awareness of options means gender biases impact decisions less, and the carer gender imbalance is reduced

More people remain in work, especially women

Care needs are better met over the long term

Long-term impacts

Improved health of care recipients

Improved mental and physical health of carers

Improved workforce efficiency/productivity

Reduced gender pay and pensions gap

Increased saving for retirement

Less benefit expenditure

The potential solutions explored in this project look to encourage behaviours to improve these short-term outcomes. They are also expected to have knock on effects for more longer-term impact, such as improved mental health of carers or a reduced pensions gap.

Information needs

Below is a condensed list of information needs identified by research and the Community of Practice. A fuller list is available in Appendix B of the report: *Supporting potential carers to make more informed decisions about work and care,* which may be found via the following link: Carers’ Employment Digital Discovery and Care Choices reports

As a potential carer, to make an informed decision, I need…

- … to consider my own needs as well as those of others, and to have information that doesn’t cause feelings of guilt I might experience around doing this.
- … signposting that uses language and terms I recognise and relate to so that I understand it is relevant to me.
- … actively served information that is accurate, up-to-date and reflects my current options (bearing in mind the system of support and services changes frequently at both the national and local level).
- … accurate, up-to-date information about the needs of the person who requires care, now and over time.
- … an understanding of what caring activities will need to be performed in order to meet those needs (early on in my journey).
- … information that is neutral, balanced and presents a full range of possible short- and long-term outcomes (including not doing any direct caring) so that I feel empowered to reach the decision that is right for me and don’t feel directed down a particular path by it.
- … information and practical advice about how to negotiate with others.
- … advice on how to advocate for myself and the person with care needs.
- … options offered to me by my current employer that would help me to combine work and any caring activities I take on and the legal rights and entitlements of carers in the workplace.
- … help to understand the long-term financial implications of my care choices and the financial support available.

2. Methodology

Prototyping, timeline, and collaboration with UAL

UAL collaboration

Policy Lab and DWP partnered with the Social Design Institute at University of the Arts London (UAL) to prototype new policy ideas. UAL funded two design graduates, Jada Bruney and Jessie Zhang to join the project managed by the Policy Lab. An additional student project was also organised by David Preston, at Central Saint Martins, UAL, which brought radical, more speculative thinking to the challenge area.

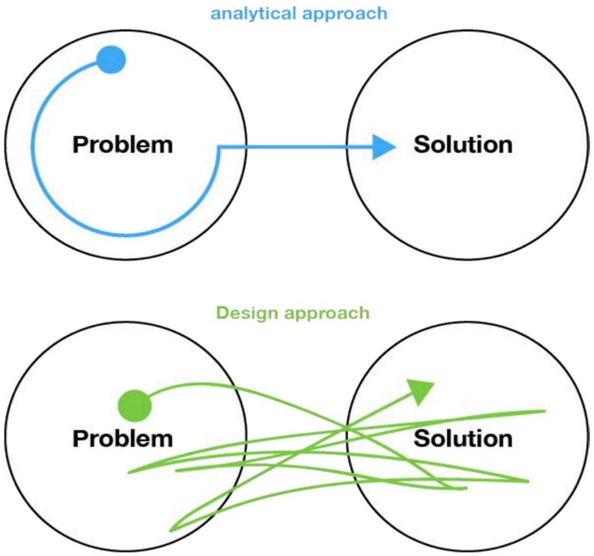
Find further information about the Design and Policy Network - funded by the Arts and Humanities Research Council.

What is Prototyping?

A prototype is a quick and basic realisation of an idea.

Developing a full-scale solution is time consuming, expensive and impossible to get right straight away. Prototyping allows us to share an idea and rapidly learn how it may or may not work to better understand a problem and the needs of users to inform a further iteration towards a solution.

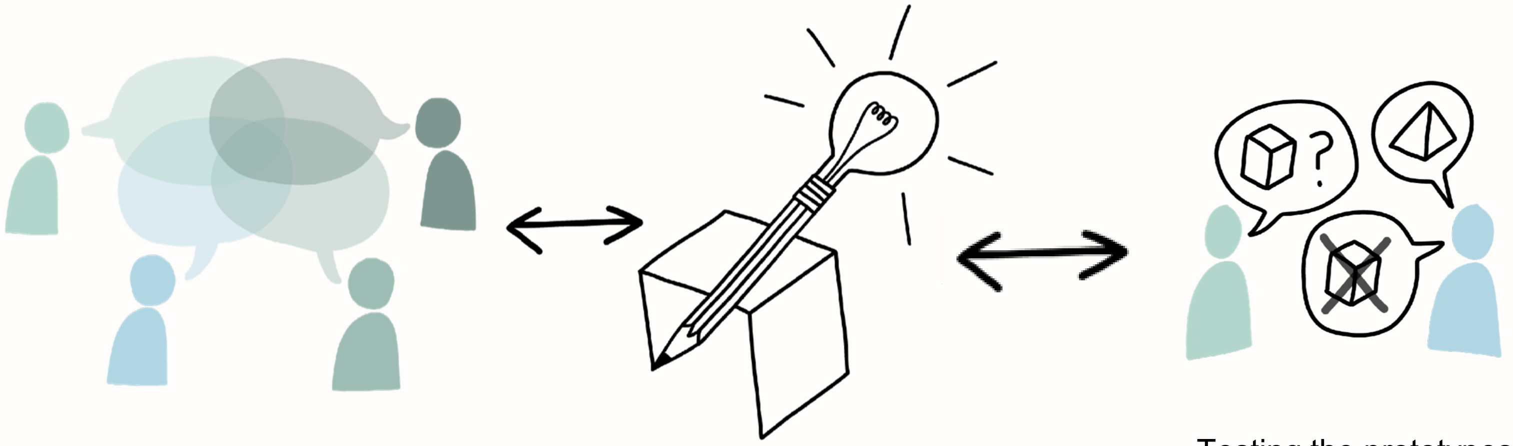
Our prototypes were not intended to be perfect. Instead, they were used as conversation starters to learn more about the experiences of carers and pave the path for next steps.



Policy Lab approach

Policy Lab ran a series of workshops with the Community of Practice to develop potential solutions, designing prototypes to mock up possible interventions which were then tested with carers.

Prototypes were iteratively developed throughout.



Ideation workshops with the Community of Practice

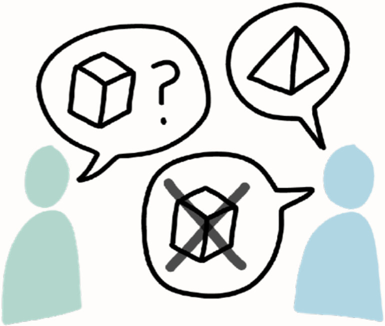
Prototyping by Policy Lab and UAL designers - Jada Bruney and Jessie Zhang.

Testing the prototypes with focus groups of carers

Participants

Policy Lab engaged a range of internal and external stakeholders through community of practice workshops, focus groups and expert interviews. During the project timeframe, we were unable to engage carers within 12 months of them learning of a friend or relatives' care needs, so instead we engaged established carers who recalled their experiences retrospectively.

Three workshops with the Community of Practice: 20-30 internal and external stakeholders from academia, government and NGOs along with carers from Tower Hamlets Carers Centre



User testing focus groups with seven carers from Tower Hamlets Carers Centre and civil service carers networks

Interviews with four professionals from charities and carers' networks and a working carer from Tower Hamlets Carers Centre

Project process: 4+ months, 4 workshops, 4 designers, 60+ participants

DIAGNOSIS
(December ‘21)

Challenge setting session with internal stakeholders (DWP, OEO, DBT, DHSC) to understand and define the problem

DISCOVERY
(January ‘22)

A ‘sprint’ workshop unpacking barriers for accessing information and making decisions to exploring creative solutions with 30+ experts from across government, non-governmental sectors, academia and carers.

DEVELOPMENT
(January - February ‘22)

Policy Lab & UAL designers develop prototypes based on sprint ideas

TESTING
(early March 2022)

Testing prototypes with internal and external stakeholders through a community of practice workshop

ITERATION & USER TESTING
(March ‘22)

Further iteration of prototypes and testing them further through 3 x user testing focus groups and expert interviews

PRESENTING OUTPUTS & NEXT STEPS
(March - April ‘22)

Presenting the outputs to internal external workshop through a community of practice workshop and defining next steps

Methodology strengths

- Gathering additional insights into barriers and opportunities related to potential carers and carers information provision choice architecture.
- Using prototyping to rapidly test a range of ideas and quickly identify what could be developed further as well as any missing functionality.
- An engaging approach with interactive workshops which resulted in high participant satisfaction.
- Reinforcing a cohesive stakeholder community of practice and defining high principles for future engagement of the group.

Methodology limitations

- Participants for user testing were only recruited through two routes (Tower Hamlets Carers Centre and Civil Service carers' networks).
- User testing was conducted with a limited number of people and further testing will be required.
- Testing was done with established carers (i.e. those who had been providing care for more than 12 months), rather than the target group of potential carers: those at the very earliest stages of making decisions about work and care.
- Some areas of interest like employment are very complex and more time is needed to unpack them to design meaningful prototypes.

Stakeholders’ feedback on the design approach

> [I liked] how the same issues and challenges were viewed differently, depending on a person's expertise. For example, how the designers took away our contributions and turned those into prototypes - sometimes the original messaging / intention was changed. But the iterative nature of the process meant there was further chance to comment and contribute. I really liked that.

Participant feedback

> I thought the balance of time between presentations and discussion was spot on. Not always the case in consultation events! I really liked the iterative nature of the work, so we could see where our ideas were incorporated and developed.

Participant feedback

3. Challenge questions

Challenge-setting workshops

We ran two challenge-setting workshops, one internally with DWP, DHSC, OEO and DBT colleagues and one externally with the Community of Practice. The aim of the sessions was to review the existing evidence and translate it into clear challenge statements to focus the prototyping stage of the project.

ıatements that have
ɔeen identified.

ve...
and maintain
ɪent and up to date
ation to support
ɪtial carers across a
se information system?

How can we...
motivate long-term thinking amongst potential carer's when considering care options and looking to balance paid work and care activities?

How can we...
support potential carers to identify as a potential carers in order for them to begin their decision making journey?

This assumes identification as a carer is necessary, when information might do better to use language that resonates with its target audience.

How can we help people understand the potential long term implications of caring sooner, to identify choices that are relevant to them?

How can we... ensure potential and actual carers continue to have choices open to them to best manage caring for another person?

n we provide and
ıain information,
out adding more
ɔmplexity to the
eady-existing info
landscape?

How can we provide information that de-stigmatises and removes the guilt associated with certain options?

How can we
support p
weigh up
complex
under st
circumst

How can we support people in making difficult trade-offs?

Hı
information to the specific needs of individuals/groups, given the diversity of carrers? (i.e. ensure they have enough information, but aren't bombarded)

How can we reflect the geographical diversityof provision

How c
better
peopl
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across
culture

How can we establish effective arrangements for ongoing community collaboration and innovation over the long term?

How can we involve the stakeholder community to achieve a sense of collective ownership of the resulting digital resources

How can we support the network of info providers to imrove infomration and services upstream in their journeys

How can we accellerate people's access to information

How can
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How can we make people aware of where to go for more information?

ow can we better engage with organisations who epresent carers from ifferent communities and ethnicities?

How can we help people to have constructive conversations with employers and family members?

How can we help people to recognise that they don't need to assume a 'primary carer model' and distribute ca

How can we help people to have potentially challenging and emotionally charged conversations with friends and family about care options?

How can we make people aware of the options for meeting care needs?

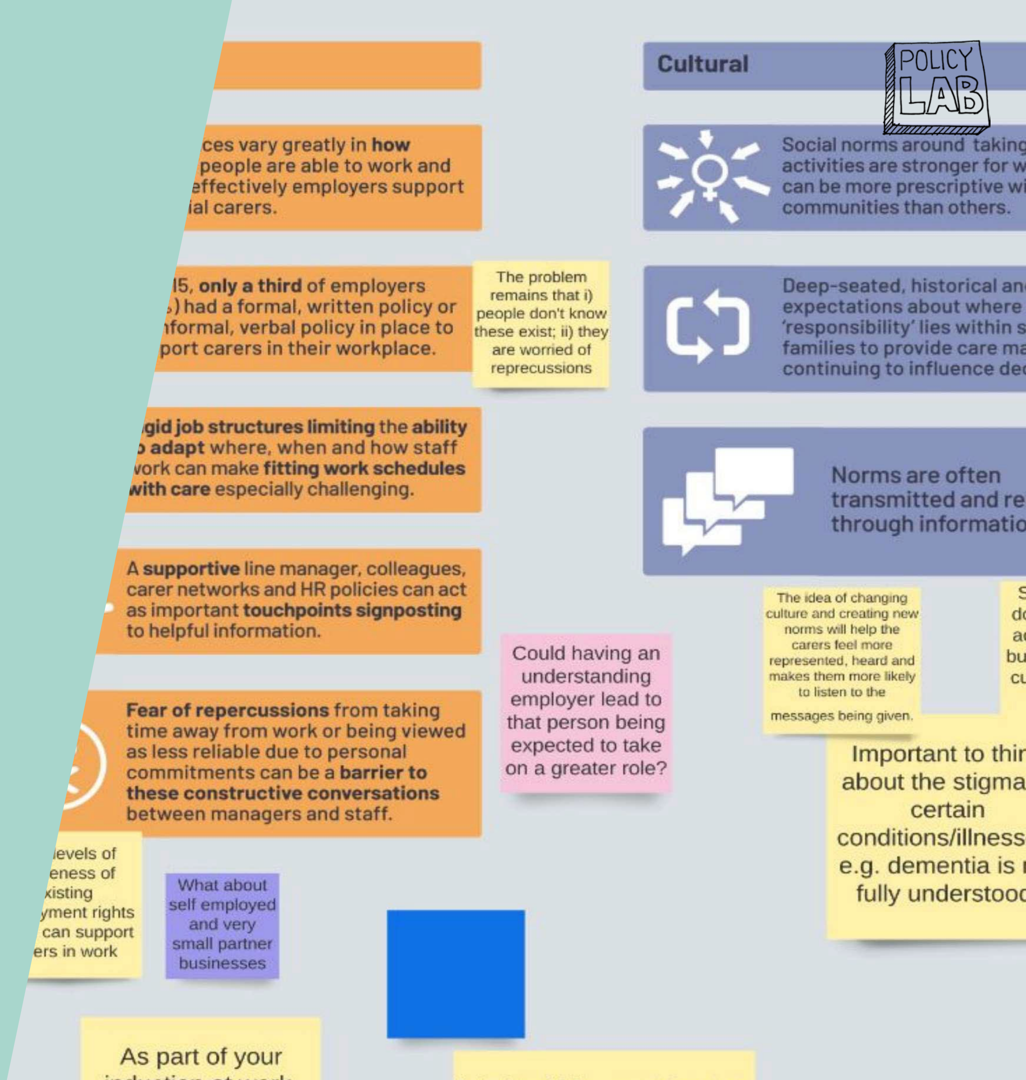
How can we shift people's perception of care as a task of an individual, to a task of a community?

Evidence Discovery

We translated the existing evidence into digestible evidence cards, which we shared in the challenge-setting workshops as an evidence discovery. The evidence cards used are included in this report's annex, available by clicking this link: **evidence cards.**

An evidence discovery is designed to be a more visual and non-hierarchical experience of information, enabling multiple people to view and contribute to an issue simultaneously. It is an opportunity to review what we already know, add additional evidence, and identify gaps in knowledge.

You can read about the evidence base in greater detail in a report titled *Supporting working people to make informed decisions about work and care* that can be found on the following webpage: Carers' Digital Discovery and Care Choices reports.



POLICY LAB

Cultural

Social norms around taking
activities are stronger for w
can be more prescriptive wi
communities than others.

ces vary greatly in **how
people are able to work and
effectively employers support**
ial carers.

l5, **only a third** of employers
) had a formal, written policy or
nformal, verbal policy in place to
port carers in their workplace.

The problem remains that i) people don't know these exist; ii) they are worried of reprecussions

Deep-seated, historical an
expectations about where
'responsibility' lies within s
families to provide care ma
continuing to influence de

gid job structures limiting the **ability
adapt** where, when and how staff
work can make **fitting work schedules
with care** especially challenging.

Norms are often
transmitted and re
through informatio

A **supportive** line manager, colleagues, carer networks and HR policies can act as important **touchpoints signposting** to helpful information.

The idea of changing culture and creating new norms will help the carers feel more represented, heard and makes them more likely to listen to the messages being given.

Could having an understanding employer lead to that person being expected to take on a greater role?

Fear of repercussions from taking time away from work or being viewed as less reliable due to personal commitments can be a **barrier to these constructive conversations** between managers and staff.

Important to thir
about the stigma
certain
conditions/illness
e.g. dementia is
fully understood

levels of
eness of
xisting
yment rights
can support
ers in work

What about self employed and very small partner businesses

As part of your

Challenge questions

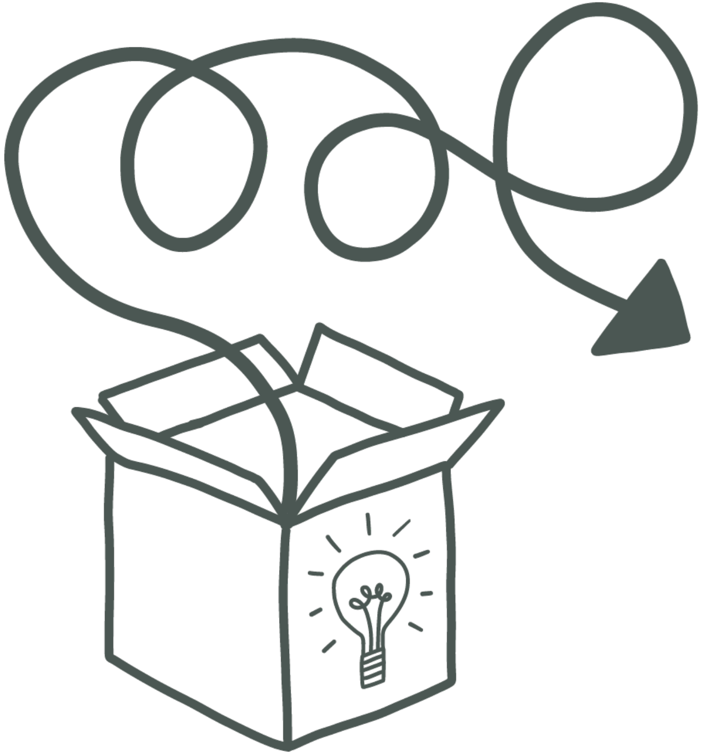
During the initial challenge-setting session with internal stakeholders, participants explored a range of evidence around barriers and opportunities.

Based on these insights and subsequent discussions, seven challenge questions were synthesised and grouped into three themes becoming the focus for the Community of Practice ideation workshop.

	Outreach & communication
1	*How can we enable potential carers who don't recognise themselves in the language of 'care/carers' to find and use the information they need?*
2	*How can we proactively identify and serve people with information about care choices, and combining care and work, using existing touchpoints and relationships?*
	Decision making
3	*How can we enable potential carers to give their own needs due weight when making decisions about work and care?*
4	*How can we help people consider long-term implications of caring in their early choices?*
5	*How can we help people to weigh up a wide range of relevant information, including their options, needs and values from multiple sources to come to an informed decision?*
	Supporting collaborative decision making
6	*How can interactions between potential carers and their employers be improved to support informed decision-making?*
7	*How can we support more collaborative decision-making about care, for potential carers to access support from others?*

4. Prototypes

Overview of the prototypes that were developed by Policy Lab and UAL designers and tested with the Community of Practice and carers



Prototype strands

Working with the DWP's Human-Centred Design Science team and UAL graduate designers, Policy Lab synthesised the ideas generated from the idea sprint workshop and clustered them into five strands related to the challenge questions. These served as a basis for the development of Policy Lab and UAL's prototypes.

Strand 1: Raising awareness

Ideas for a communication campaign to encourage potential carers to seek support.

Challenges:
Outreach & communication

Strand 2: Information navigation

A range of tools for helping potential carers navigate the complex information landscape.

Challenges:
Decision making

Strand 3: Sharing real experiences

Ideas for a communication campaign to connect with potential carers, help them make sense of their situation and encourage them to seek support.

Challenges:
Outreach & communication
Decision making

Strand 4: Conversation support

Tools and guidance for having challenging conversations around planning and managing care options.

Challenges:
Supporting collaborative decision-making

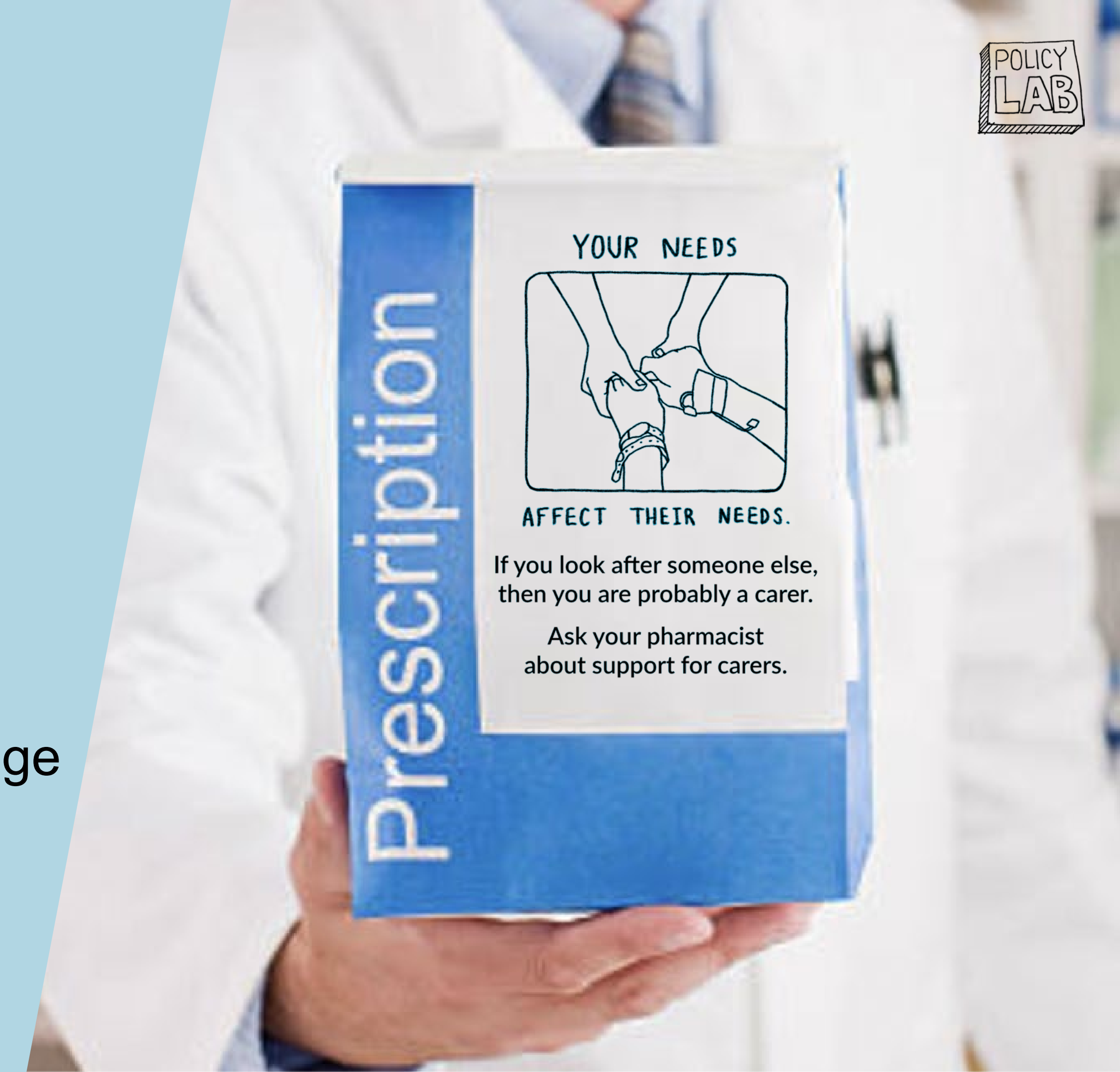
Strand 5: Supporting employers & employees

Reflections on the interactions between working carers and their employers and how they can better serve the needs of potential carers.

Challenges:
Supporting collaborative decision-making

Strand 1: Raising Awareness

Ideas for communication campaigns to connect with potential carers, and encourage them to seek support.



If you look after someone else, then you are probably a carer.

Ask your pharmacist about support for carers.

Initial thinking: barriers to address & initial hypotheses to explore.*

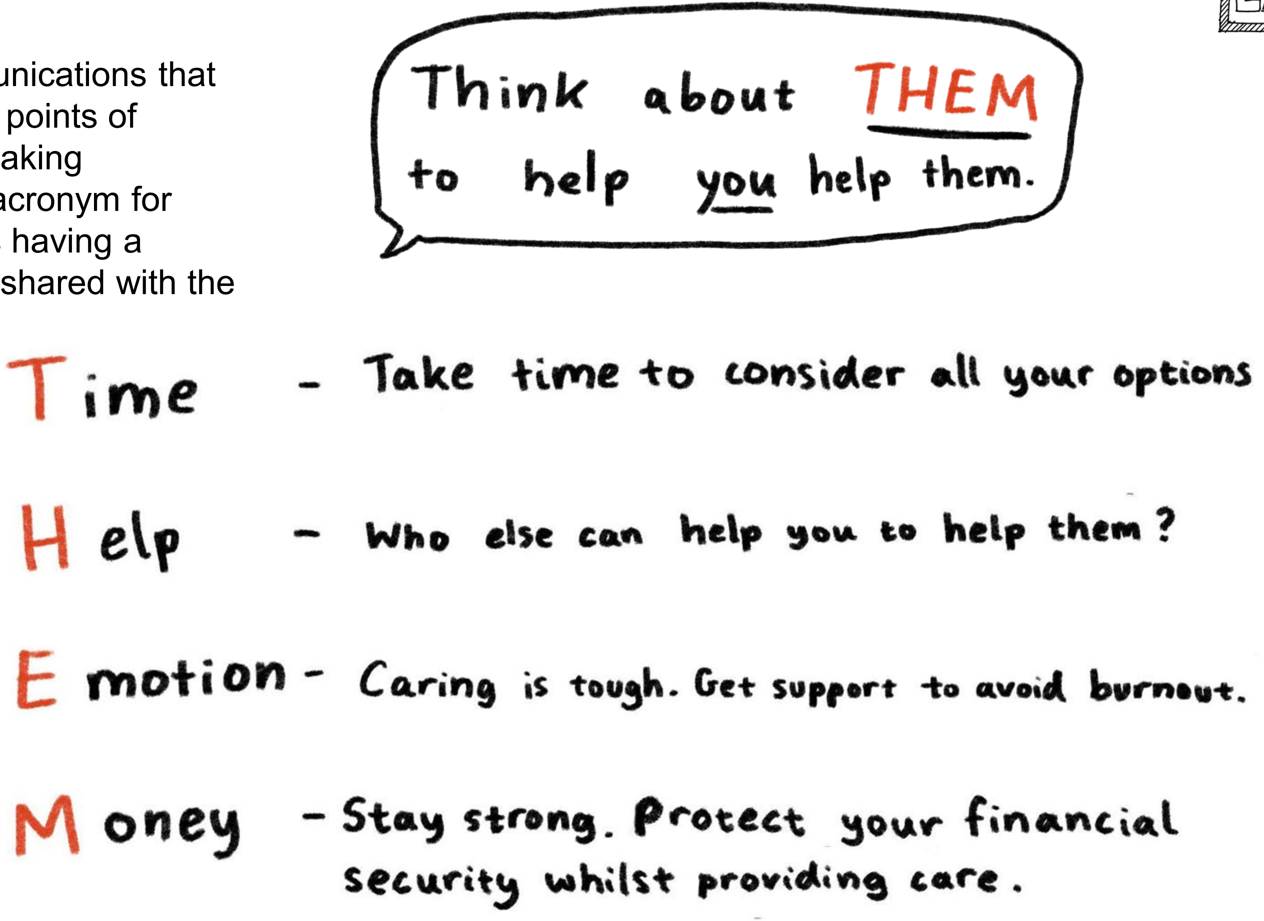
Raising Awareness

Barriers to informed decision making	Proposed solutions	Assumed outcomes
Many potential carers initially do not identify as carers and can take many years to recognise their activities in the language of care the term.	Avoid using the language of care or caring in campaign messaging. Identify touch points to proactively engage with potential carers.	More potential carers will recognise themselves within the language of care earlier and engage with information sooner.
Information is fragmented and overwhelming.	Create a concise and memorable advice campaign (like ‘FAST’ for strokes) to support decision making.	Potential carers will consider a range of options and the long-term implications of caring.
Potential carers often give more weight to the needs of the person with care needs and feel guilt when doing so.	Through messaging, align the needs of the potential carer with those of the person with care needs.	Potential carers see value in considering their own well-being as important to provide the best care possible.
Making decisions about care can be emotionally challenging and stressful.	Use messaging and visual tone that is reassuring and calm.	Potential carers will feel less stress and more able to make decisions.

***through testing, the proposed solutions and assumed outcomes were changed as reflected in the suggestions**

Advice campaign

Initially we explored communications that sought to deliver a few key points of advice to potential carers, taking inspiration from the FAST acronym for identifying someone who is having a stroke. This prototype was shared with the Community of Practice.



Think about THEM to help you help them.

Time - Take time to consider all your options

Help - Who else can help you to help them?

Emotion - Caring is tough. Get support to avoid burnout.

Money - Stay strong. Protect your financial security whilst providing care.

Insights from Community of Practice stakeholders:

There was support for the approach of asking **who is looking after you whilst you are looking after someone else** but others felt that potential carers may not feel this messaging is aimed at them, and that it **felt more targeted at those already caring**.

The amount of advice was considered information overload at an early stage, and due to the diversity and complexity of care situations, risked becoming **ambiguous or unclear**.

There were concerns about the othering of overstating THEM as an acronym, it was felt that this **could feed into existing stigma** around caring.

It was also raised that messaging needs to make it clear that **carers have choices about what - if any - kinds of caring to do**.

Key Challenges:

The **nuances and variations of care situations** makes it difficult for a generic campaign to engage the diverse mixture of potential carers.

Not everyone has the **luxury of time** to process their need when becoming a carer. In health and social care situations there are assumptions that you have to make immediate decisions.

Potential carers **won't necessarily understand the pressure or guilt of caring** at the stage that they haven't started caring or haven't realised they are a carer.

Suggestions:

Due to the limitations of an advice campaign, it was advised that it would be more appropriate to focus on **signposting people to a care specific service** - an expert resource or appropriate professional.

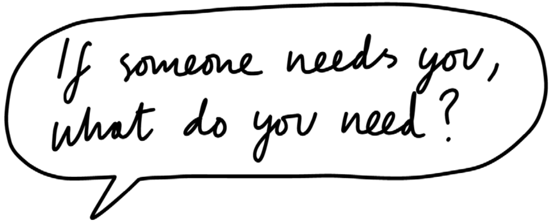
Option 1

Call to action campaign

We moved from the advice campaign to a more straightforward call to action campaign. We tested a range of different visual and messaging options (this slide and next). These prototypes were shared in one user testing session before being tweaked slightly for two more sessions.

Option 2

Option 3



Raising Awareness

Option 4

Option 5

Insights from user testing:

Option 1 was **liked** by participants.

“Option 1 - I like visuals on that. As carers you are looking after everybody so I do connect with that.” Carer [as part of user testing]

A **key criticism** was that the messaging across the options was **confusing**; a potential carer would not necessarily know it was for them, and the ‘offer’ was **unclear**.

One suggestion was to communicate to potential carers that they **need to act before their health deteriorates**. Another view was that the term ‘crisis’ was problematic, suggesting that **if in a crisis space you might be in denial**.

Another suggestion was that the imagery showed **predominantly older people** and felt more like an advert for bereavement rather than caring. This aligned with previous feedback from the Community of Practice to **acknowledge the diversity and complexity** of care situations.

Suggestions:

Within the current system, the **language of care and caring**, whilst not to be used in the headline, **needs to be acknowledged in some way** to help **unlock the support and services** available. Ideally identification as a carer should not be a prerequisite for receiving support, but this requires significant system change.

The **call to action** needs to be **clear** and **signpost** to a specific location. Where should we be signposting potential carers to?

It is important to **represent** the **diversity** of care situations.

Call to action campaign development

Building upon important feedback from the first user testing session, the copy on the call-to-action posters was developed. Additionally, the option showing care for a younger person was included in line with feedback we had received.

We also introduced a range of signposting options to ask the question of where we should be directing potential carers for further information.

Option 1 - versions used in the final two user testing sessions

You are here for them.

Who is there for you?

If you are helping someone,
then you could be a carer.

You are not alone.

Talk to us now to understand your options.

www.hereforyou.com

You are here for them.

Who is there for you?

If you are helping someone,
then you could be a carer.

You are not alone.

Talk to us now to understand your options.

www.hereforyou.com

Option 3 (L) and Option 4 (R) - versions used in the final two user testing sessions

If you look after a friend or family member,
then you are probably a carer.

Get help and advice to support you both.

Visit your local Carer's Centre.

If you look after someone else, then you are probably a carer.

Get the support you need now before it impacts your health.

Talk to your GP today.

Insights from user testing:

Participants responded **positively** to….

… the inclusion of the image of **caring for a young person in Option 1.** We heard that those who care for children and partners are **slower to identify** as carers than those caring for the elderly, and that there can be **stigma around parents identifying as carers for their children** as it is just seen as parental responsibility.

… positioning the needs of the carer alongside those of the person with care needs. One carer commented: *"If you don't look after yourself, who will look after the people you're caring for?"*

… the drawing style and handwritten typography with appreciation that it felt *"nice and friendly".*

Key Challenges around **inclusion** were raised by various participants. The **red and green** used in option 1 images presents **legibility issues** for people with **colour-blindness**. **Handwritten typography** presents problems for **neurodiversity inclusivity** such as for people with autism (N.B. all copy was handwritten but this was updated between user testing sessions 3 and 4).

Suggestions:

Further **emphasis** on **representing a rich diversity** of care needs and carer identities is important to reach as many people as possible.

Complex and emotional decisions often need to be made quickly so there is a **need to balance urgency and reassurance**.

Be **mindful of inclusivity** when making design decisions.

In terms of **signposting**, we learnt that…

… the benefit of being signposted to a website was that it was an **"unthreatening" ask** for potential carers and **could be accessed on their own terms**.

Key Challenges:

Discussing carer needs with a GP was **dependent on the relationship** and **how proactive** that GP was in engaging with potential carers.

Care Centres are helpful spaces but **potentially intimidating environments** for people at the early stage of their journey. If you were uncertain about being a carer, you might not feel confident asking for help. It was also highlighted that they can be **difficult to access for working carers** as many are only open from 9 to 5.

Some care situations can be met with **stigma or are challenging to discuss**, such as supporting someone with severe mental health problems or substance misuse. Caring for someone with autism was raised as challenging as the condition is often dismissed as just bad behaviour and/or poor parenting.

"Carers' centres are very helpful but I would not walk in [at an early stage], it would scare me." Carer (via user testing)

There are **limitations to a national awareness campaign** with support services **varying across different localities**.

"Getting people to access support is a very local thing: what is available in Coventry is very different to what is available in Birmingham." Carer (via user testing)

Suggestions:

Consideration needs to be given to how a potential carer can be guided through information because it is often **overwhelming.**

Any nationwide campaign would need to **signpost toward more local sources** of information to be helpful.

Develop a greater understanding of varying levels of stigma surrounding certain conditions/illnesses and care situations (this was also highlighted as an evidence gap during challenge-setting workshops).

Utilising key touchpoints

We heard from the Community of Practice workshop that printed materials can sometimes struggle to connect and that face-to-face interactions work best so we developed thinking to try to combine the two.

In our user testing we shared a prototype of a prescription bag showing a call-to-action message that encouraged the potential carer to ask the pharmacist about support for carers.

We asked participants what other touchpoints would work for engaging potential carers.

Insights from user testing:

Participants **responded positively** to the idea and suggested the following touchpoints for engaging potential carers:

- **Banks** when managing someone else's finances
- **Supermarkets, online shopping** pop-ups or leaflets with **deliveries** when organising another's **shopping**
- **Schools or public playgrounds**.
- **Hospitals** were raised as moments where **more effort should be made to signpost** potential carers to information and support. An **equivalent of a Family Meeting focused on a carer's needs** was suggested as an idea to better support potential carers along with **embedding condition-specific specialists in hospitals** (e.g. someone from the Stroke Association) to offer specific advice.
- **GP surgeries** were also considered **important**, especially at **moments of diagnosis**, with a need to **focus more** on the **needs of the potential carer**.
- **More experienced carers** were mentioned by some as helpful. One carer suggested adding a **digital signature or badge to the end of emails** to act as a conversation starter in the workplace.

Suggestions:

Combining campaigns with physical and in-person touchpoints could be more impactful.

Co-locate carers' services in healthcare settings to create more space and time for conversations about carer needs.

Help potential carers connect with active carers to harness collective wisdom of those with experience.

Insights from Community of Practice:

Key Challenges:

Resources and capacity will vary across signposting contacts. It is important to understand limitations and capabilities - “who can actually pick up the phone?”

Filtering to the right organisation (local, national, condition specific, specialities of information, etc). How do you provide the right option for different users?

GP surgeries can be quite disparate groups to work with. For more strategic work, it is better to work through **primary care networks** (groups of GP practices) which take a more system based, population management approach than many GPs surgeries do.

There can be resistance from GPs to top-down direction.

There can be a lot of resistance from GPs to do anything apart from getting elected care access back up to where it was previously.

Measures of success could include:

- reducing the time it takes for people to identify as a carer (the average is two years according to research by Carers UK). However, the wider goal should be to remove the prerequisite of identification to access information.
- an increase in proactive sharing of information amongst localised networks such as community WhatsApp groups.

Suggestions:

Coordinate closely with signposting contacts to make the best use of their resources and capacity.

Adopt an area-based approach within a system and evolve solutions for working in different areas (e.g. rural and urban).

Work through primary care networks.

Allow for localised adaptation of tools and processes to increase ownership and encourage adoption.

Identify trade associations and business umbrella organisations as touchpoints for employers.

Use survey data to identify gaps in carer identification to better target campaigns.

Summary of suggestions: enabling potential carers to recognise themselves as carers and better integrate the existing touchpoints

Raising Awareness

Signposting:

Focus campaigns on a clear call to action that signposts to a care-specific service - an expert resource or appropriate professional.

Any service needs to offer a signposting mechanism toward more local sources of information to be helpful.

Information is overwhelming and making sense of a care situation is challenging, so consideration needs to be given to how a potential carer can be **guided through.**

Challenge: With limited time for decision making, how much can a potential carer's sensemaking be handled sensitively?

Coordinate closely with **signposting contacts** to make the best use of their **resources and capacity**

Touchpoints:

Combining campaigns with **in-person touch points** could be more impactful. Allow for **localised adaptation** of tools and processes to **increase ownership and encourage adoption**.

Co-locate carers services in healthcare settings to create more space and time for conversations about carer needs and signpost to information.
Work strategically through **primary care networks.**

Help **active carers** identify potential carers to harness their collective wisdom.

Identify **trade associations and business umbrella organisations** as **touchpoints for employers**.

Summary of suggestions: enabling potential carers to recognise themselves in the language of caring and better integrate existing touchpoints

Language and messaging:

Avoid using only the language of ‘care’ and ‘caring’ in headlines to engage those who do not yet identify as carers.

However, within the current system, the terminology does **need to be acknowledged in some way** to help **unlock the support and services** available. Ideally, systemic efforts should be made to make this not so.

It is important to **represent** the **diversity** of care situations to reach as many people as possible. Evidence gaps in understanding differing norms, expectations and roles across genders and different socio-economic and cultural groups were highlighted during challenge setting workshops.

Design principles:

Be **mindful of inclusivity** when making aesthetic design decisions. An engagement with inclusive design principles is important for ongoing work.

Complex and emotional decisions often need to be made quickly so there is a **need to balance urgency and reassurance**. As such, developing language and messaging requires expertise in copywriting to achieve a productive balance.

Strategic targeting:

Adopt an **area-based approach** within a system and evolve solutions for working in different areas (e.g. rural and urban).

Trade off: Permitting localised agency over messaging and touchpoints will encourage ownership but reduce centralised control over communications.

Use survey data to identify gaps in carer identification to better target campaigns.

Raising Awareness

Looking forward

What could be done next?

Focus on utilising touchpoints.*

Identify areas across key regional variables to target for more specific testing.

Prioritise touchpoints to focus on (pharmacies, supermarkets, banks, GP surgeries, schools…) including digital touchpoints (such as online supermarkets and loyalty cards).

Work with communication experts and local stakeholders to further develop prototypes.

Plan and run location-specific trials across the key touchpoints with a focus on engaging potential carers.

Further questions to explore:

Which touchpoints are most effective for reaching potential carers?

What opportunities and challenges do different touch points offer? What is their willingness to work with Government?

What language, messaging and visuals best help potential carers seek support?

How do approaches need to differ across different regions?

What data is there on geographic differences in care needs and provision?

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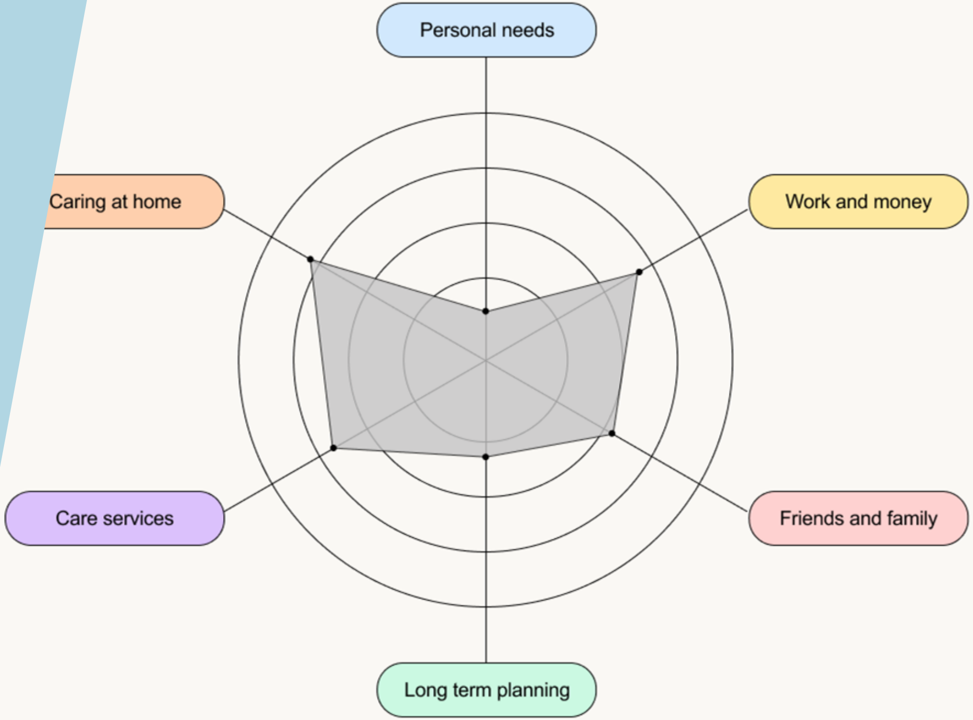
* Utilising touchpoints could help identify potential carers to test other prototypes with (e.g. podcasts and digital tools).

Strand 2: Information Navigation

A range of digital experiences were explored helping potential carers navigate a complex information landscape.



Initial thinking: barriers to address and initial hypothesis to explore through user testing.*

Information Navigation

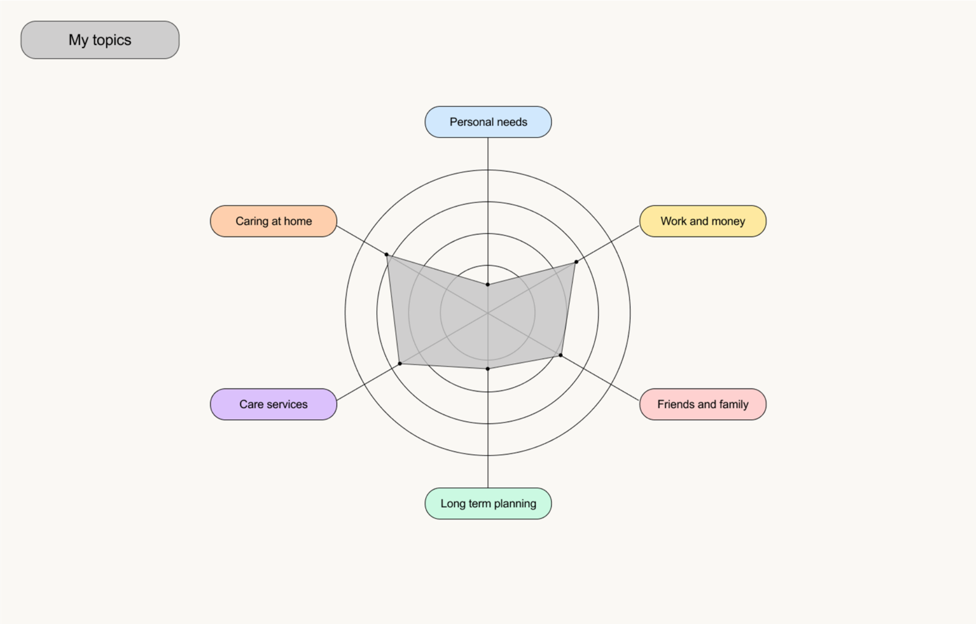
Barriers to informed decision making	Proposed solutions	Assumed outcomes
Many potential carers don’t know where to access information and can be overwhelmed by the amount available. Many potential carers are time pressured and have difficulty locating useful information at a time that works for them.	Use staggered onboarding to quickly identify gaps in knowledge and signpost to further reading. Break down information into small, task-focused sections.	It will be easier for potential carers to locate the information that they specifically need and become better prepared to make decisions around care. Gaps in knowledge can be filled quickly with easily digestible tasks, successfully improving knowledge.
Care journeys are all different. Potential carers need information that is relevant to their specific situations and point in their journey.	Tailor information to current level and appetite through an information navigation tool that is constantly calibrating to the users’ needs.	Ensures information is always relevant to the care journey which saves time and results in more focused and mindful decision making, hopefully reducing stress and burnout.
A potential carer’s wellbeing can become low priority when caring for a loved one. This can have a detrimental effect on the health of the potential carer as well as the person with care needs.	Prompts for the user to consider their own needs and keep a long-term perspective during decision making.	Potential carers will have a better understanding of the caring landscape and what they can expect on their journey. They will be able to make better long-term decisions which will benefit their wellbeing resulting in better care given.

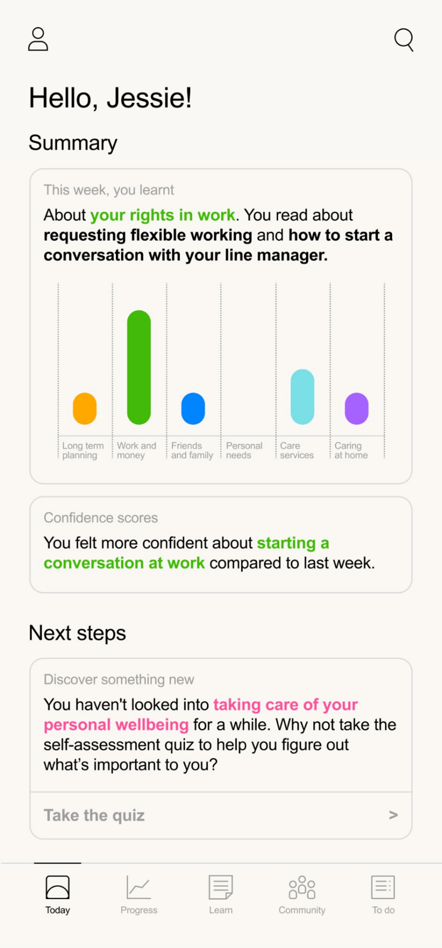
***through testing, the proposed solutions and assumed outcomes were changed as reflected in the suggestions**

Information Navigation

Visual progress tracking

This is the first prototype we showed the Community of Practice that proposed using progress tracking to allow potential carers track their journey through information and show them where they had paid the most and least attention.





Hello, Jessie!

Summary

This week, you learnt

About **your rights in work**. You read about **requesting flexible working** and **how to start a conversation with your line manager.**

Confidence scores

You felt more confident about **starting a conversation at work** compared to last week.

Next steps

Discover something new

You haven't looked into **taking care of your personal wellbeing** for a while. Why not take the self-assessment quiz to help you figure out what's important to you?

Take the quiz >

Information Navigation

Insights from Community of Practice workshop:

Engaging with information as a potential carer can be overwhelming. If highlighting areas of low engagement, you need to break down the problem into small actionable tasks - the NHS “5 Ways of Wellbeing” was highlighted as a good example of action-orientated information.

An overly complex digital app could put off people who **just need to get a task done**.

Progress tracking could be **demotivating** and risks putting off potential carers.

If you put the **onus on the potential carer to know what information they need** there is a risk being limited to the world that they can perceive.

Suggestions:

Tools need to help potential carers **look beyond what they know.** Information tailoring must start by **learning the users’ particular needs** and contain **feedback loops** to continuously adjust the content.

Information should be **task focused** and delivered **piece by piece** in response to needs.

Frame onboarding processes as a **self-assessment tool** rather than progress tracking.

Testing digital experiences

We reframed our approach based on initial feedback gathered from carers on three different digital experiences. To ensure our learning supported DWP digital, we focussed less on details about any specific app. Instead, we asked wider questions about user needs and preferences for digital interaction.

These were:

1. A customisable app or website that responds to carers' information needs
2. A Gov.uk page that signposts carers to key information.
3. Utilising social media platforms to create peer to peer networks for sharing information.

Customisable app

The customisable app was explored further. Focusing on a less direct approach to assess information needs and prompt toward less familiar information and follow up actions.

1. Users sign up and create a profile so that progress can be saved and tracked

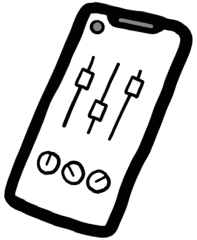
2. The app asks some starter questions to allow the user to self-assess their information confidence for important topics such as health, care activities, work, money and well-being

3. The app then provides a visual representation of the users' confidence for these topics

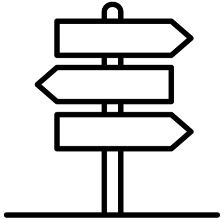
4. The user can click on a topic to explore suggested information resources to learn more about this area

5. After reading, users can save resources for later and are asked again to self-assess their information confidence levels.

6. In response to these answers, users are served with options for further reading.



Information Navigation

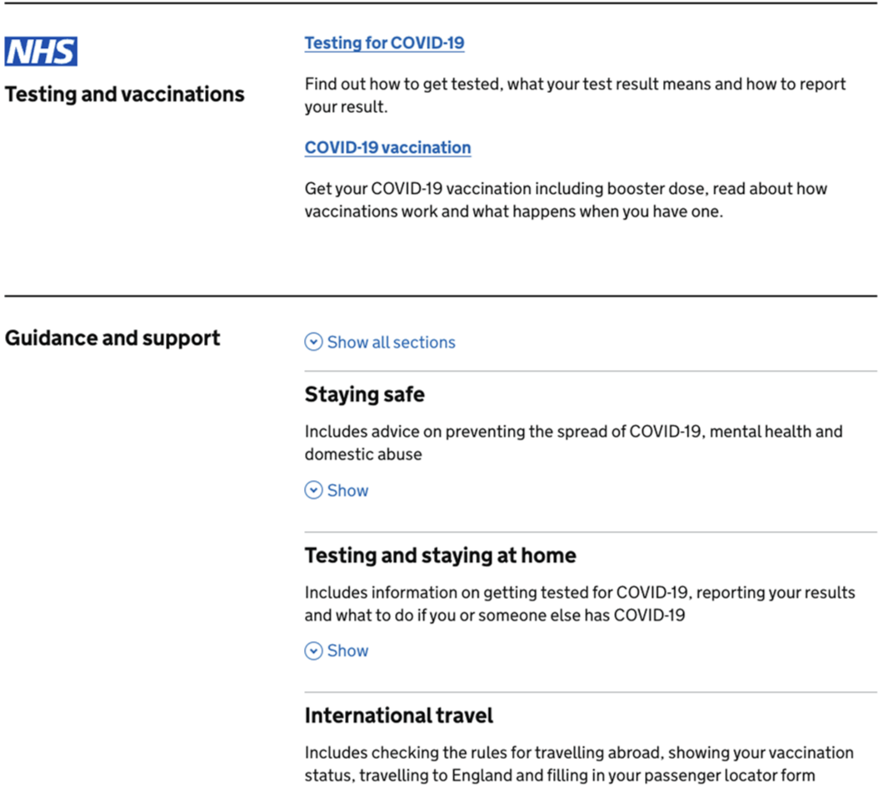


Gov.uk signposting

[Please note that this hypothetical testing of gov.uk signposting was conducted prior to the creation of signposting on the Job Help pages for carers]

We explored whether signposting from Gov.uk could direct users to key information. Signposting could follow GDS without providing a specific service. We shared an example of Gov.uk signposting for Covid-19 to test the format with carers.

Hypothetically, key services could be presented at the top of the page (this could be a link to a Carer's Assessment or to find your local Carers Centre) and contain links to relevant information, listed by topic and clearly titled.



NHS

Testing and vaccinations

Testing for COVID-19

Find out how to get tested, what your test result means and how to report your result.

COVID-19 vaccination

Get your COVID-19 vaccination including booster dose, read about how vaccinations work and what happens when you have one.

Guidance and support

Staying safe

Includes advice on preventing the spread of COVID-19, mental health and domestic abuse

Testing and staying at home

Includes information on getting tested for COVID-19, reporting your results and what to do if you or someone else has COVID-19

International travel

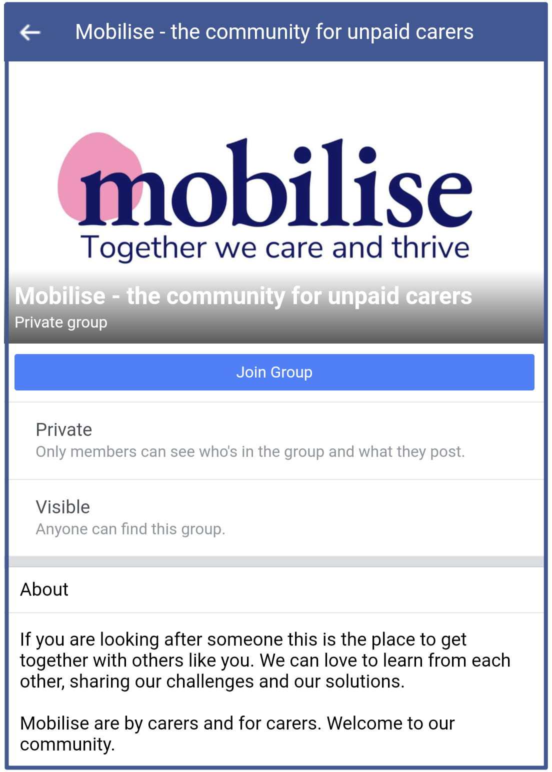
Includes checking the rules for travelling abroad, showing your vaccination status, travelling to England and filling in your passenger locator form

Social Media platforms

We proposed utilising familiar social media platforms (such as Facebook) to create peer to peer networks for sharing information. Platforms offer the ability to join up with thousands of people and share insights instantly.

For example, Mobilise offer a Facebook community specifically for carers. Carers UK hosts an online community for carers. Community Facebook groups, where residents can share questions and information about the area were also tested with users.

facebook



Mobilise - the community for unpaid carers

mobilise
Together we care and thrive

Mobilise - the community for unpaid carers
Private group

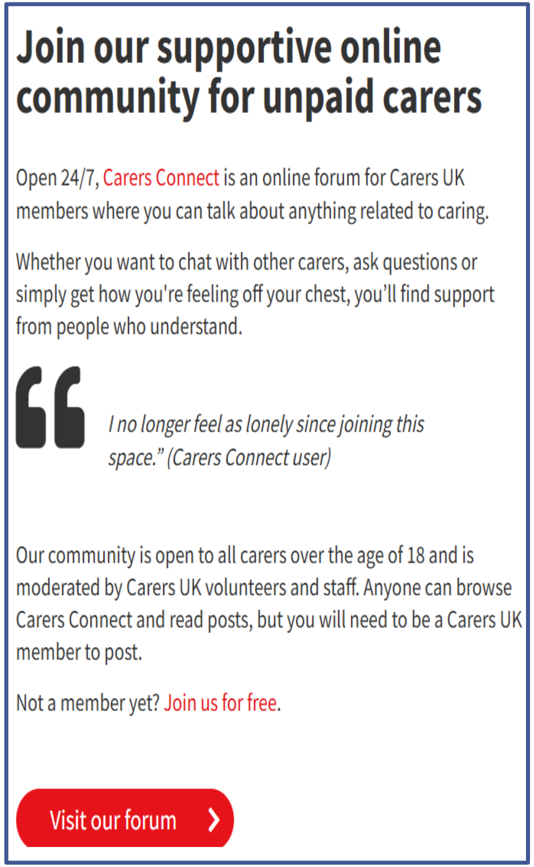
Private
Only members can see who's in the group and what they post.

Visible
Anyone can find this group.

About

If you are looking after someone this is the place to get together with others like you. We can love to learn from each other, sharing our challenges and our solutions.

Mobilise are by carers and for carers. Welcome to our community.



Join our supportive online community for unpaid carers

Open 24/7, Carers Connect is an online forum for Carers UK members where you can talk about anything related to caring.

Whether you want to chat with other carers, ask questions or simply get how you're feeling off your chest, you'll find support from people who understand.

> *I no longer feel as lonely since joining this space." (Carers Connect user)*

Our community is open to all carers over the age of 18 and is moderated by Carers UK volunteers and staff. Anyone can browse Carers Connect and read posts, but you will need to be a Carers UK member to post.

Not a member yet? Join us for free.

Summary of insights from user testing with carers:

Customisable app:

- The effectiveness of any app would rely on its intuitiveness and ability to be up to date and relevant.
- Information for potential carers is very overwhelming. Delivering key information first would be preferable.
- Many potential carers are hidden, and it would be challenging to make sure that any app reaches them.
- An app would work for some but not all. Many carers already use apps for other services e.g. online banking, ordering an Uber, shopping online. However, an app would not work for those who lack digital or literacy skills.

Gov.uk signposting

- Whilst not excited by it, participants trust Gov.uk
- For many carers, Gov.uk, a Local Authority website or NHS online would be their first port of call, making these good spaces to signpost to other resources or digital products.
- The simplicity of design was welcomed. Information can be overwhelming for potential carer so a **'less is more'** approach was deemed important.

Social Media platforms:

The carers we spoke with highlighted these benefits:

- The systems are well designed and intuitive to use.
- Facebook groups can be useful for getting local information from carers in the same area.

They also raised these problems:

- Social media is a palace for subjective opinions and could become a source of false information.
- Facebook is a place where people retreat from caring and it should be protected as such.
- Lots of groups on Facebook are national and not local which may not offer the in depth support you might need.

Summary of suggestions: consider various aspects of making a digital tool accessible, tailor information and make online content reliable.

Consider digital capabilities

Any digital intervention requires a **hybrid approach** (a combination of digital engagement and human contact points e.g. phone/video calls) due to a variety of preferences for engagement.

Combine **digital tools** with **human support** to help those who struggle with technology.

Information should be delivered in **digestible formats** as **task-focused and actionable.**

Information can be overwhelming for potential carer so a **'less is more'** approach was deemed important.

Challenge: A digital tool is only useful if it reaches the potential carers who need it.

Digital tools need to be **proactively served** to the people who need them.

Trade-off: Social media platforms can be used as spaces for retreat from caring.

Tailoring information

Tools need to help potential carers **look beyond what they know.** Information tailoring has to start by **learning of the users' particular needs.**

Tailored advice requires **feedback loops** for **continual recalibration** to **stay up to date** and **relevant** to user needs.

Frame onboarding processes as **self-assessment tools** rather than progress tracking to **avoid creating demotivating experience.**

Development challenges

Challenge: Apps can be time consuming, expensive and complex to design. If funding runs out then you risk not being able to continue development.

Challenge: Testing tools with potential carers requires care as the tool cannot risk breaking when they are doing something critical.

Online credibility

For many potential carers, Gov.UK or a Local Authority website would be their **first port of call**, making it a good **signposting hub.**

Social media can easily **spread false information** so **moderation is necessary** to ensure credibility.

Information Navigation: Looking forward

What could be done next?

A more in-depth mapping and assessment of the digital tools available, developing an understanding of resource demands and risks.

Develop prototype Gov.uk signposting to a range of engagement options from digital services to help lines and in-person services.

Discuss this and a range of existing options with potential carers as well as other apps and digital services that they use regularly.

Convene a working group within the Community of Practice around digital navigation to discuss how Government and Gov.uk can support their existing work.

Within the working group, co-develop a set of principles with potential carers in mind.

Further questions to explore:

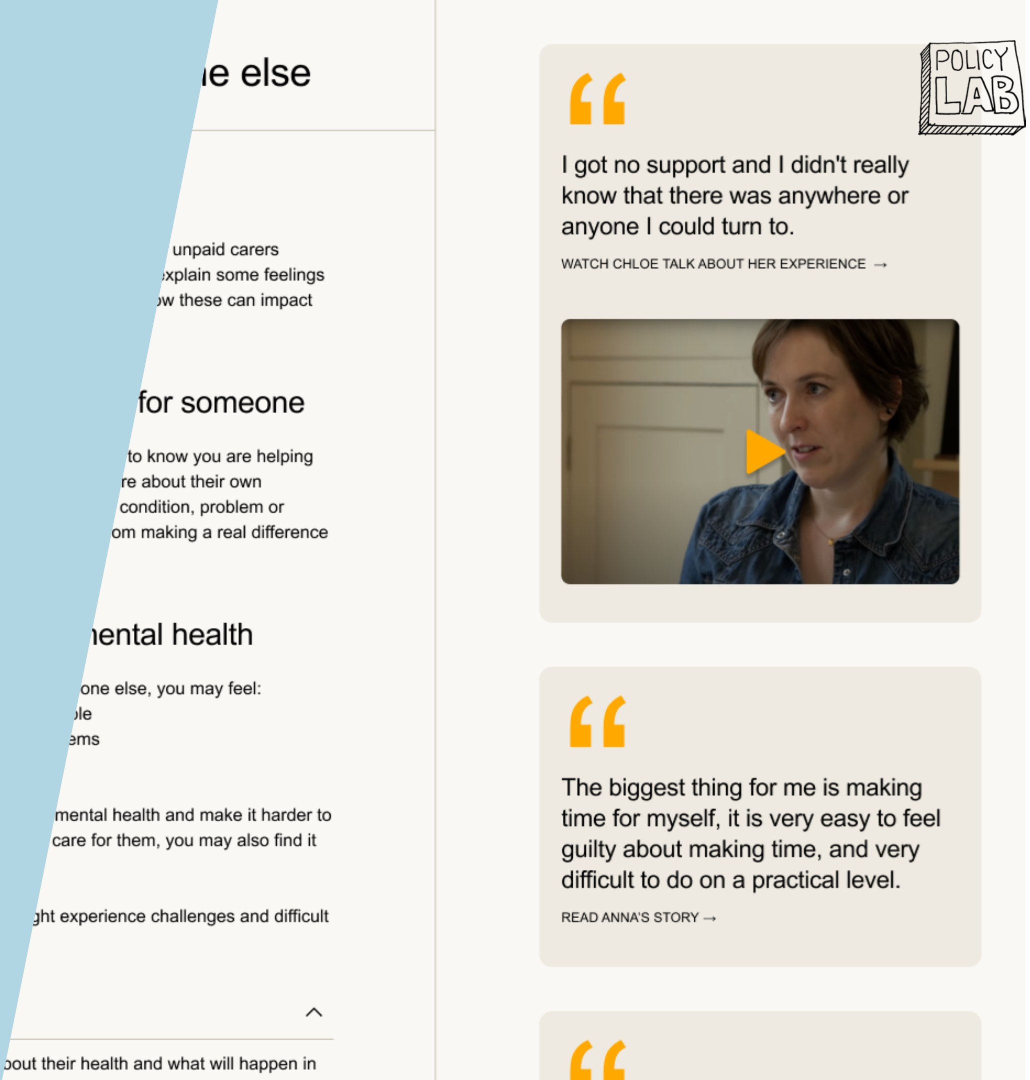
Which existing tools are most effective for engaging potential carers?

How can Government best support existing tools and services?

What could Gov.uk signposting look like and how effective can it be for supporting potential carers?

Strand 3: Sharing Real Experiences

Integrating stories to make the sense-making experience more human, helping potential carers to identify with others and feel less isolated when exploring options.



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> I got no support and I didn't really know that there was anywhere or anyone I could turn to.

WATCH CHLOE TALK ABOUT HER EXPERIENCE →

> The biggest thing for me is making time for myself, it is very easy to feel guilty about making time, and very difficult to do on a practical level.

READ ANNA'S STORY →

Initial thinking: barriers to address and initial hypotheses for exploration.*

Sharing Real Experiences

Barriers to informed decision making	Proposed solutions	Assumed outcomes
Lots of written information can make it hard for potential carers to engage with and digest. Potential carers have limited time to engage with information.	Offer a range of multimedia sources of information including video and podcasts.	Multimedia sources cater to different ways of learning making it easier for more people to engage with information. Audio information can be engaged with whilst doing other things saving time. Saving time and alleviating stress.
Many potential carers don't recognise themselves in the language of care.	Position a wide variety of care experiences from a diverse range of voices alongside information.	Seeing a diversity of experiences makes it easier for potential carers to recognise themselves within the language of care.
Potential carers find it difficult to consider the long-term implications of care and give little weight to their own needs.	Show accounts of real carers discussing their experiences and the long-term implications of caring, emphasising the importance of considering your own needs as a carer.	Potential cares are more likely to engage with advice from people who have lived experience.
Potential carers are often struggling with stress and burnout.	Use real voices and human faces to deliver important information.	The human experience makes potential carers feel less isolated and reduces feelings of stress.
Having conversations around sharing care activities can be challenging.	Make podcast/video segments easily shareable.	Friends and family are more likely to watch or listen to content and engage more with the human quality, becoming more open to helping.

***through testing, the proposed solutions and assumed outcomes were changed as reflected in the suggestions**

Carers Podcast

Listening has unique benefits over other forms of informational engagement. A prototype that we explored was a carer's podcast. Podcasts are an episodic series of audio files that users can download to their phones or computers and listen to at a time of their choosing. They are normally done in a conversational, informal way. A key advantage is that carers can listen whilst doing other activities.

Peer-to-peer support

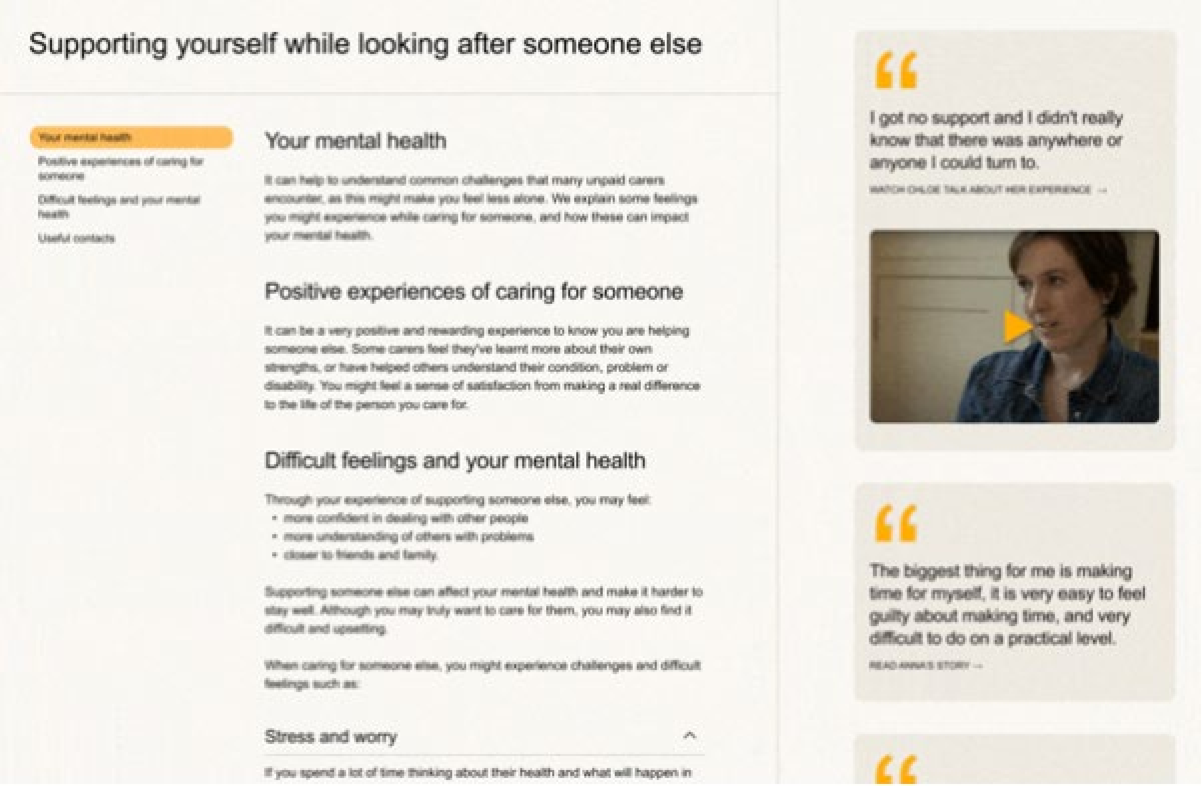
By sharing experiences and advice, carers may feel more empowered to take decisions and feel less alone in their situation. Another aspect of podcasting, and about sharing stories more generally, is that **stories can humanise caring**.

The informal nature of podcasting could also render challenging topics less daunting; be it talking about accessing financial benefits or addressing the subject of bereavement for example.

Sharing Real Experiences

Integrating lived experience

We also developed a prototype for how written information and multimedia content could be displayed together using two complementary scrolling channels. In this way, information can be shown alongside a diverse range of stories and accounts from real life carers.



Supporting yourself while looking after someone else

Your mental health

It can help to understand common challenges that many unpaid carers encounter, as this might make you feel less alone. We explain some feelings you might experience while caring for someone, and how these can impact your mental health.

Positive experiences of caring for someone

It can be a very positive and rewarding experience to know you are helping someone else. Some carers feel they've learnt more about their own strengths, or have helped others understand their condition, problem or disability. You might feel a sense of satisfaction from making a real difference to the life of the person you care for.

Difficult feelings and your mental health

Through your experience of supporting someone else, you may feel:

- more confident in dealing with other people
- more understanding of others with problems
- closer to friends and family

Supporting someone else can affect your mental health and make it harder to stay well. Although you may truly want to care for them, you may also find it difficult and upsetting.

When caring for someone else, you might experience challenges and difficult feelings such as:

Stress and worry

If you spend a lot of time thinking about their health and what will happen in

> “
> I got no support and I didn't really know that there was anywhere or anyone I could turn to.
>
> WATCH CHLOE TALK ABOUT HER EXPERIENCE →

> “
> The biggest thing for me is making time for myself, it is very easy to feel guilty about making time, and very difficult to do on a practical level.
>
> READ ANNA'S STORY →

Insights from Community of Practice workshop:

Utilising multimedia accounts of lived experience was received positively by many in the group. We heard that…

- Caring is often an isolating experience. Learning from real people can help potential carers **realise they are not alone in their experiences.** Knowing that there are others going through similar experiences is powerful.

- **Audiovisual media can help information be processed more easily** and be **more inclusive**.

- **Caring decisions can be value-laden and emotional,** so it is important to hear lived experience stories. It's easier to 'get' where a person is coming from via voice, than by text.…it allows for **hearing the emotion** in stories which is a key element to decision making that might not come through via text. **Peer to peer support works well.**

- It's easier to **continue doing other tasks** whilst listening. Listening could happen **whilst waiting** for a carers appointment **you can be listening to advice** on preparation for the conversation, **resulting in a more robust assessment.**

Suggestions:

Combining information with multimedia lived experience accounts is a powerful way to tackle the loneliness of caring.

Multimedia experiences of information can improve processing.

Strategically position content in key touchpoints to best help potential carers at opportune moments.

Key challenges raised by the Community of Practice:

It is important to represent a diversity of lived experience and conditions to reach as many potential carers as possible.

Do not to duplicate work that already exists. Mobilise has thousands of carers on its network and shares real stories.

Podcasts are a saturated market and potential carers may not find the podcast or take the time to listen.

Long podcasts may not be suitable for everyone, as they can be difficult to digest and people may not remember the content.

Producing content is time consuming.

Content can quickly become out of date. Some content can be generic and time-spanning. But there is some content that would need to be updated which is a real commitment.

The DWP brand might not be considered entertaining.

Podcasts may only be suitable for certain demographics or users. Suggesting that alternative means of sharing stories should be considered

Suggestions:

Aim to represent a **rich diversity** of caring lived experience.

Engage with channels that have the target audience on it will be key e.g. Money box audience.

Learn from those already exploring podcasting in this space.

If developing podcasts, do so in a **range of languages** to reach more people.

Supplement podcasts with **key summaries** of information.

Test and understand what length and format of podcast works well for users. Snippets of interviews discussing specific topics or issues.

Podcast topics carers suggested would be valuable to hear discussed at the outset of a caring journey:

- What is care? Who is a carer?
- Acknowledging that you are a carer
- Available support and how to access it.
- Financial advice/benefits
- Joining a local carers centre
- How to apply for benefits
- Health networks and accessing support.
- The importance of respite
- Dealing with Local Authorities
- Setting up power of attorney, appointeeship.
- Other legal information; will, trusteeship, inheritance packs, probate.
- Avoiding bad habits and negative behaviours (e.g. substance misuse)
- Loneliness, social isolation, tunnel vision, exercise
- The importance of finding and joining relevant charities

Further insights from User Testing:

Podcasting was **popular** amongst carers we shared it with, even if they did not already listen to podcasts.

Stories are crucial, hearing how someone has tackled the same challenges and their experience.

We heard that it is **important to balance serious information with humour**.

Peer support was highlighted as hugely important for connecting on a human level. Care centres can be difficult to access for working people. Condition-specific support charities were seen as helpful.

Time to listen was raised as an issue, with some care situations making it difficult to find peaceful moments to listen.

“What is available in Coventry is very different to what is available in Birmingham.”

It is important that information is localised so there is a question about how helpful a podcast can be if it talks to a national audience.

One carer questioned whether the complexity of care topics would be challenging to communicate via a podcast and would instead **need to be seen visibility**, for example using a flow chart.

Suggestions:

Utilise storytelling.

Balance information with humour and entertainment.

Connect stories to associated peer support groups.

Keep content short and focused - snippets of interviews discussing specific topics or issues.

Produce region specific content.

Supplement podcasts with visual materials if possible to represent complex information or processes.

Summary of suggestions: humanise the narratives around caring, make most of existing channels, improve accessibility of content and keep it useful.

Make it human

Utilise storytelling - **combine information with multimedia lived experience** accounts is a powerful way to mitigate the loneliness of caring.

Aim to represent a **rich diversity** of carers lived experiences.

Balance information with **humour and entertainment**.

Connect stories to relevant **peer support groups**.

Partnerships

Learn from those already exploring podcasting in this space.

Engage with channels that have the target audience on it will be key e.g. Money box audience.

Capabilities

Multimedia experiences **can improve information processing**.

Develop stories in a **range of languages** to reach more people.

Keep it useful

Produce **region specific content**.

Strategically position content in key touchpoints to best help potential carers at opportune moments.

Keep content **short and focused** - snippets of interviews discussing specific topics or issues.

Supplement podcasts with **key summaries** of information and **visual materials** to represent complex information or processes.

Looking forward

What could be done next?

Identify a range of partners to learn more about and support the development of a podcast series aimed at potential carers - this could be the Community of Practice

Ask potential carers which of the topics identified through our conversations with carers are of highest priority to them

Develop content, both audio and visual, about the key topics of interest. Create a working group to co-create the messaging and identify a diverse range of people with caring experience to review the content.

Test and iterate content with potential carers.

Further questions to explore:

What is the optimum length for podcast/video content?

How can the content be best organised and accessed?

How should multimedia content be combined with other information sources?

How can we engage and even entertain potential carers in this content whilst remaining trustworthy and credible?

Where should potential carers be signposted to?

Who is best placed to deliver this content (capability and public face)?

How would potential carers find the content?

How can the effectiveness of multimedia engagement be measured?

How can potential carers be supported remember relevant information?

Strand 4: Conversation Support

Tools and guidance for having effective conversations around planning, managing, and sharing care, designed to be accessible at critical moments, helping potential carers advocate for their needs.

How to be assertive:

- **Be simple and direct.** Don't leave room for misinterpretation. Assertiveness is effective because it is straight to the point.
- **Practice your assertiveness skills.** Practice what you're going to say. Try roleplaying with a partner or friend.
- **Body language.** Keep a neutral face expression, sit up tall, make eye contact to show confidence.

Initial thinking: barriers to address and initial hypotheses for exploration.*

Conversation Support

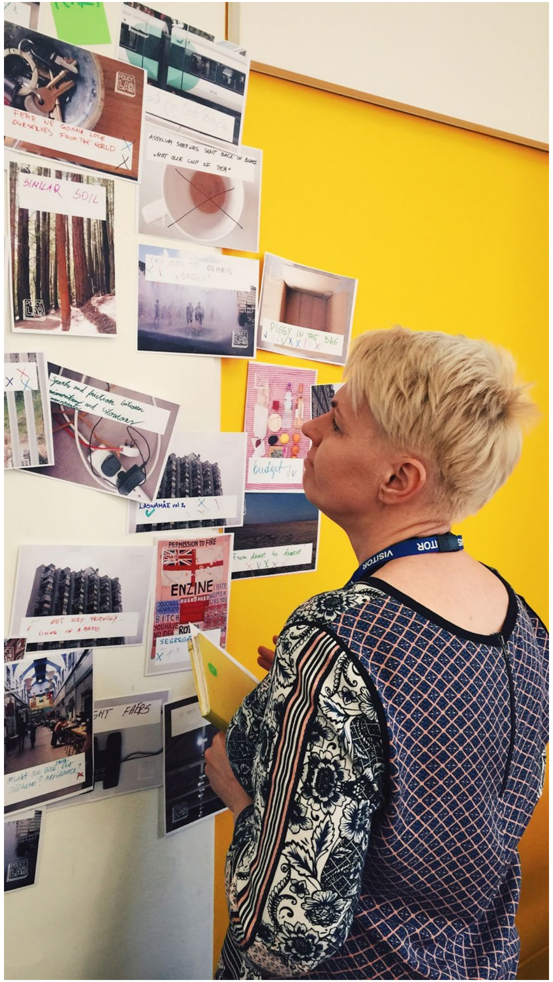
Barriers to informed decision making	Proposed solutions	Assumed outcomes
Time pressure – it is difficult to find time when collaborative conversations can happen.	A text messaging chatbot could help potential carers access the information that they need for their specific conversation more quickly and effectively. Advice shared via concise, bullet points for ease of use.	Potential carers can easily access information in moments of down time such as transit. Targeted and concise advice can be easily read through. Potential carers are empowered to engage with advice and have better conversations as a result.
A difficult family situation and challenges in resolving conflicting views make it difficult to explore care options and compromises for sharing care. Cultural norms or roles defined early on can limit sharing of care activities.	Conversation advice delivered in compact and easy to access takeaways (for example as text messages or wallet size cards) for use in moments of conversation.	Potential carers can easily access advice when most needed, resulting in focused and constructive conversations and better sharing of care. In the moment prompts support self advocacy, useful for those working against cultural or social pressure.
Stress and burnout - conversations about care are difficult for all those involved.	Having easily accessible advice, or advice that is positioned in strategic locations where potential carers visit and needs advice, such as waiting rooms.	Potential carers access advice in high stress situations where their capability to remember key points or self-advocate is usually hindered, resulting in a conversation that works better for them.

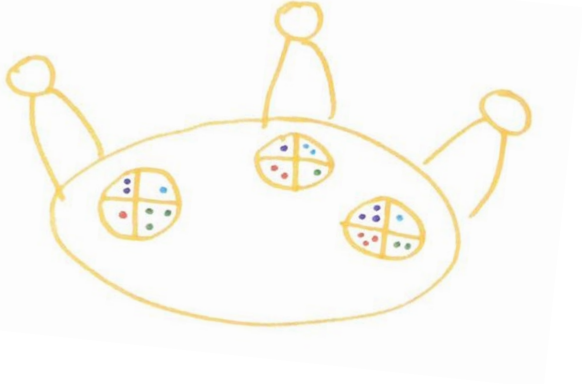
***through testing, the proposed solutions and assumed outcomes were changed as reflected in the suggestions**

Conversation Support


I hope to have time to walk outside


I fear I won't have time to spend with family



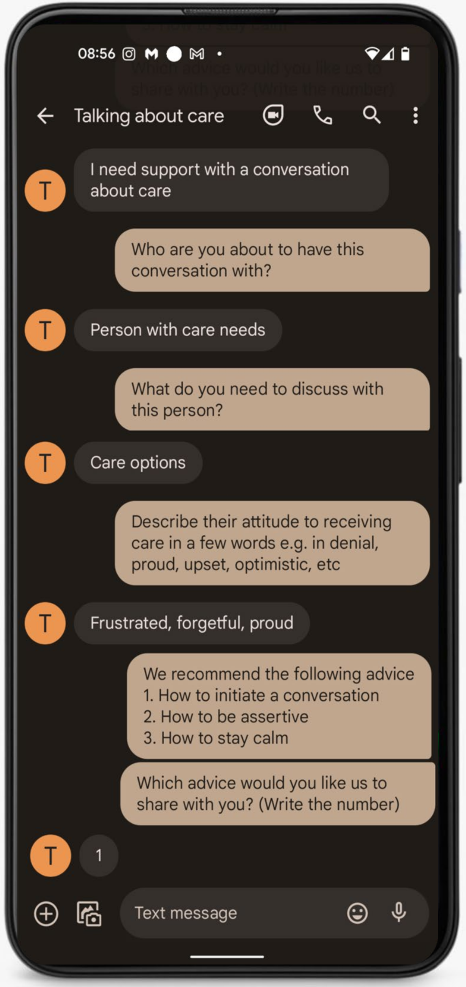


Conversation Tools

In the first Community of Practice workshop, we initially shared prototypes of tools for facilitating conversations, but the feedback was that they were too formal and would feel forced.

It was clear from the discussion that people wanted advice rather than direction. So we developed ideas with this focus for our user testing sessions.

Conversation Support



T: I need support with a conversation about care

Who are you about to have this conversation with?

T: Person with care needs

What do you need to discuss with this person?

T: Care options

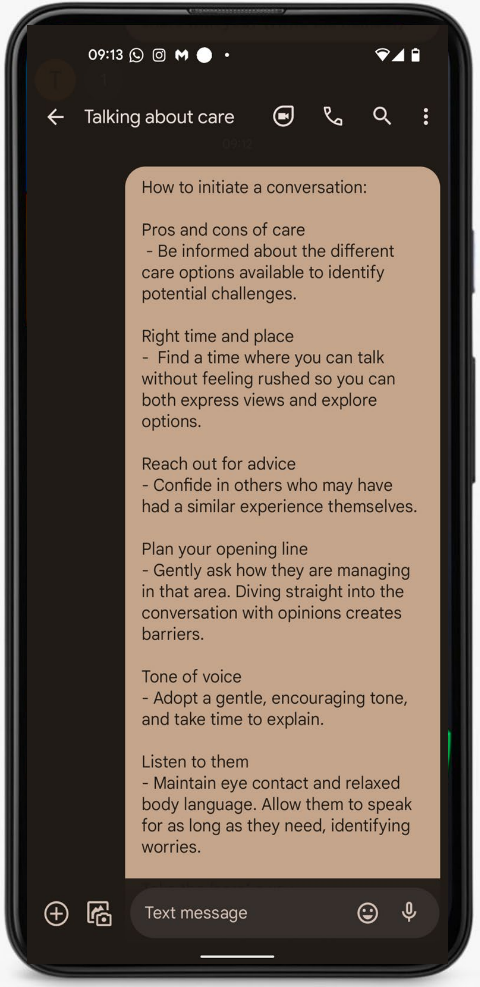
Describe their attitude to receiving care in a few words e.g. in denial, proud, upset, optimistic, etc

T: Frustrated, forgetful, proud

We recommend the following advice
1. How to initiate a conversation
2. How to be assertive
3. How to stay calm

Which advice would you like us to share with you? (Write the number)

T: 1



How to initiate a conversation:

Pros and cons of care
- Be informed about the different care options available to identify potential challenges.

Right time and place
- Find a time where you can talk without feeling rushed so you can both express views and explore options.

Reach out for advice
- Confide in others who may have had a similar experience themselves.

Plan your opening line
- Gently ask how they are managing in that area. Diving straight into the conversation with opinions creates barriers.

Tone of voice
- Adopt a gentle, encouraging tone, and take time to explain.

Listen to them
- Maintain eye contact and relaxed body language. Allow them to speak for as long as they need, identifying worries.

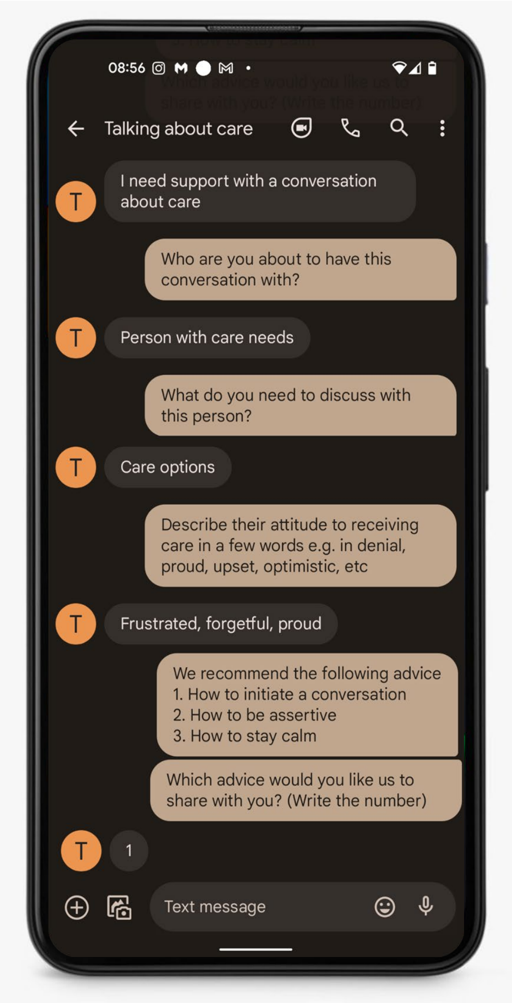
Chatbot: Conversation Advice

(These ideas were gathered in 2022, before GPT models became popular. The capabilities of chatbots are vastly different today.)

A chatbot messaging service designed to help potential carers find tailored advice for their conversation needs. The bot would ask you questions about who you are having the conversation with, the topic of conversation and the attitude of the person you are having the conversation with (are they frustrated, forgetful, proud, optimistic? etc).

Based upon the answers given, tailored advice would be delivered in a concise format (via text message or email) to be easily accessed at the point in which it is needed, either on the way to having conversations, waiting for appointments or as prompts during conversations.

Conversation Support



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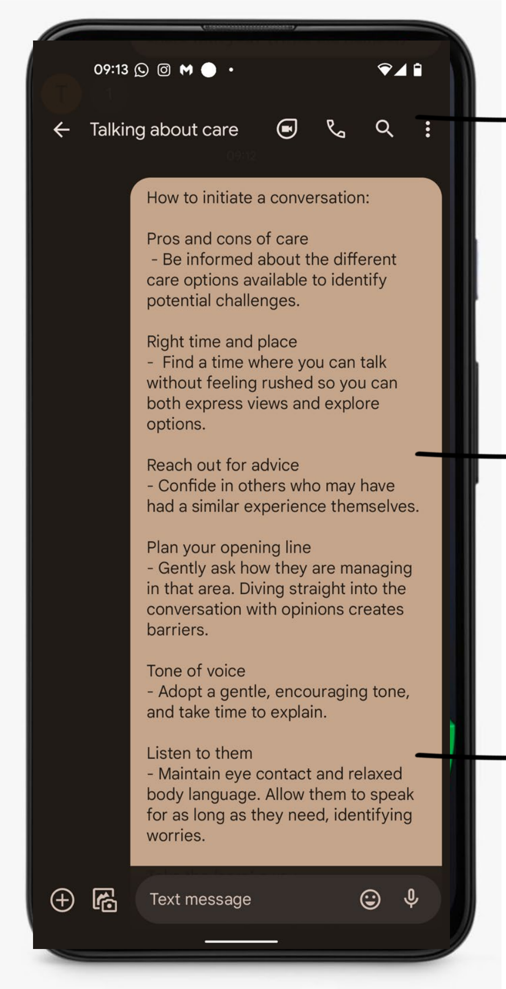


How to initiate a conversation:

Pros and cons of care
- Be informed about the different care options available to identify potential challenges.

Right time and place
- Find a time where you can talk without feeling rushed so you can both express views and explore options.

Reach out for advice
- Confide in others who may have had a similar experience themselves.

Plan your opening line
- Gently ask how they are managing in that area. Diving straight into the conversation with opinions creates barriers.

Tone of voice
- Adopt a gentle, encouraging tone, and take time to explain.

Listen to them
- Maintain eye contact and relaxed body language. Allow them to speak for as long as they need, identifying worries.

Conversation Support

"I need to speak to a healthcare professional about my needs.

And I feel uncertain."

How to be assertive:

- **Be simple and direct.** Don't leave room for misinterpretation. Assertiveness is effective because it is straight to the point.
- **Practice your assertiveness skills.** Practice what you're going to say. Try roleplaying with a partner or friend.
- **Body language.** Keep a neutral face expression, sit up tall, make eye contact to show confidence.

Initiate a conversation about care:

- **Pros and cons of care.** Be informed about different care options available to identify potential challenges.
- **Right time and place.** Find a time where you'll be able to talk about their concerns without feeling rushed.
- **Take the 'care' away.** Instead of using the words 'care' and 'carer', try using words like 'support', 'personal assistant' and 'companion'.
- **Tone of voice.** Adopt a gentle, encouraging tone, and take time to explain why.

"I need to speak to a family member about meeting their care needs.

And they are in denial."

Advice cards

A less technological alternative could be advice cards shared in strategic locations such as Carer Centres, GP surgeries or hospitals.

On one side there is a description of a challenging conversation, and on the other, points of advice. Cards are pocket sized so can be taken away and re-read at opportune moments.

Insights from user testing:

Carers responded positively to the conversation support tools, finding them useful. One reflection was that making short prompt lists was already a useful practice that they did for themselves.

There was some **resistance to the idea of a chatbot**, with a **preference for real human contact**. However, it was acknowledged that such a personalised service might require too much human resource to implement.

WhatsApp was suggested as a **potential alternative**. With just **the act of chatting being beneficial** even if you don't get the answer you need. The same participant commented on how many people have now become confident with video calls and this can be done from home or in transit.

> *"It'd be good to have some sense of a teammate throughout it, so that you're not on your own, something that's constantly there, that you can check in with, offering social things, practical advice - something you have to fall back on, so you're not just on your own."*
>
> Working carer (via user testing)

Suggestions:

Deliver advice in a **condensed and easily accessible format** that can be used during conversations.

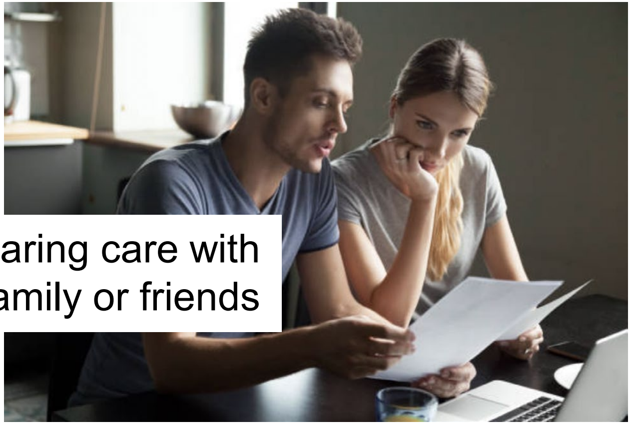
Prioritise real human contact as much as possible. Potential carers respond positively to social contact.

If using an automated system such as a chatbot, make this **explicit and obvious from the outset** to not confuse or frustrate the user.

Conversation Support

Which care conversations most require support?

We used this prompt to ask carers about challenging conversations they had to deal with in their early stages of caring and the conversations they wished they had had.


Sharing care with family or friends


Negotiating with employers


Discussing options with the person with care needs


Speaking with professionals

Conversation Support

Insights from user testing on challenging conversations:

Conversations about exploring care options with the person with care needs were raised as particularly difficult.

Carers cited elderly parents wanting to maintain independence or not ask for support to avoid being seen as a “burden” or to be making a “fuss”. Discussing the prospect of **moving into a care home** was considered particularly problematic.

Speaking with professionals (such as GPs, Occupational Therapists, District Nurses or Professional Carers) was said to be important and carries the potential for shifting potential carers’ opinions or direction of travel, and signposting to further information.

One participant wished they had received support earlier on to raise the conversation about being offered a social worker.

A significant challenge raised was the **limited time available** for these conversations. Coupled with the **emotional trauma** experienced in these moments, we heard that it was **important that potential carers were well prepared**.

When asking about experience navigating conversations with employers, one suggestion was that potential carers need **support and advice to self-advocate and make a business case** for their employers to support them. They said that ultimately, an employer’s motivation is to run a business, and that potential carers needed help to speak this language.

Suggestions:

It is important to find ways to **change the narratives and reduce stigma** around seeking professional help (especially amongst the ageing).

Provide tips for **“soft ways”** to initiate difficult conversations.

Conversations with professionals are of utmost importance but tend to be time-limited.

Provide potential carers with the support and language to **self-advocate in the workplace**.

Insights from Community of Practice:

Employers for Carers have a toolbox which includes prompts for conversations.

Consider who could be trusted in delivering a chatbot (Vodafone has developed a successful chatbot) and who could **provide a reliable source of information**.

Key Challenges:

Difficult to get the technology to work and ask the right questions. If the technology does not work, there is a risk users will feel trapped in the technology.

Requires a lot of investment upfront to get right, specifically good insights research to talk to those not yet identifying as carers.

Users may feel dissatisfied with a chatbot instead of a real person, especially if coming from Government.

Care situations are unique and specific, so generic conversation guidance may not capture the necessary nuance to be helpful.

Digital resources will not work for everyone.

Hard to create a meaningful connection through a chatbot and the experience could be dehumanising. Chatbots work better with facts rather than emotions.

Suggestions:

Connect with and learn from…

…developers of successful chatbots.

…organisations or knowledge champions to develop advice.

Explore, promote and adapt existing resources.

Co-design conversation tools with the target audience to ensure that they are applicable.

Utilise human contacts if possible. Could the responses be provided by a community instead?

Provide a **clear exit option to talk to a real person** if the technology fails.

Conversation Support

Summary of suggestions: work with carers and other professionals to help develop tools for rendering difficult conversation easier; and recognise that chatbots cannot replace human-to-human interactions.

Conversation advice:

Deliver advice in **a condensed and easily accessible format** that can be used during conversations.

It is important to **change the narratives around accessing professional help.**

Provide tips for **"soft ways" to initiate difficult conversations.**

Conversations with professionals are of utmost importance, but they have limited time available.

Provide potential carers with the support and language to **self-advocate in the workplace.**

Connect with and learn from organisations or knowledge champions to develop advice.

Explore, promote and adapt **existing resources.**

Co-design conversation tools with the target audience to ensure that they are applicable.

Automated technology (chatbot):

(Note: these reflections were made in 2022)

Difficult to get the technology to work and may not be appropriate for potential carers - chatbots are better equipped to deal with facts, not emotions. Will likely require significant investment upfront to get the offering right.

Connect with and learn from **developers of successful chatbots.**

If using an automated system, **make this explicit and obvious from the outset** to not confuse or frustrate the user.

Provide **a clear exit option to talk to a real person** if the technology fails.

Prioritise real human contact as much as possible. Look to use the caring community to provide support.

Conversation Support: Looking forward

What could be done next?

Interview chatbot developers to understand the opportunities and limitations of the technology.

Develop new prototypes that are less technology dependent (such as FAQs) and run further user testing with carers and potential carers.

Interview potential carers to understand their situation. Combine these insights with what we have heard from carers to prioritise which types of conversations to begin testing with.

In depth review of the conversation tools available. What advice exists?

Reach out to a range of knowledge experts to gather advice and assess the quality of advice available.

Convene a working group within the Community of Practice to co-create advice with potential carers and carers.

Further questions to explore:

For potential carers...

What conversations about care are you finding most challenging?

What advice do you want?

For carers and a community of practice...

Is there feasibility in a more community-driven response to this challenge?

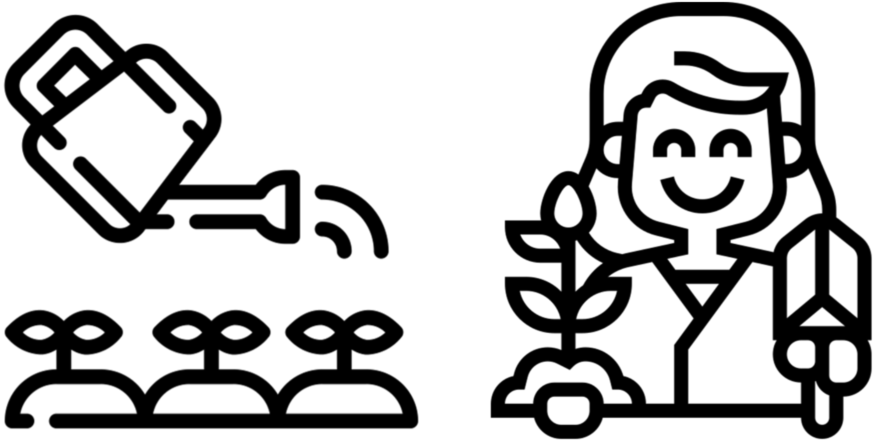
For chatbot developers...

Is the technology suitable for this challenge?

What does the technology require to make it successful? What are the risks and challenges?

Strand 5: Supporting employers

Reflections on the interactions between working carers and their employers, including how workplace culture and policies can better serve the needs of potential carers.



> *A quick retweet or a post on LinkedIn or media case studies are really powerful when a working carer talks about their experience - be it a struggle or when they are really supported.*

Charity representative (via interview)

Workplace culture

Tools and approaches are needed to facilitate a positive shift in culture and “get the idea of being a carer into people’s minds before it happens”.

Numbers and stories are particularly powerful - you can’t ignore the large numbers of employees who are and will be engaged in caring activities (1 in 4) . At the same time, stories help us step into carers’ shoes and understand what it is like to combine work and care.

> *New generations and millennials, new companies are in touch with employee wellbeing support and are encouraging a culture of sharing.*
>
> *45 and above people don't want to consider it as much.*

Working carer (via interview)

Providing support

Employers need to be supported to recognise, understand and support potential working carers' practical and emotional needs.

It's about wellbeing but also practical needs, for example unlocking financial benefits or amending their contract.

Returning to nurturing a positive working culture, it's important that employers encourage 'a culture of sharing' personal experiences and challenges which helps line manager and senior staff support potential carers' needs.

Some carers have recognised a positive trend in new companies and with younger staff who might be more attuned to mental health needs and a culture of sharing. But more needs to be done and this needs to be applied across the board and not just a few progressive employers.

Staff training, senior champions and awareness raising campaigns can all be helpful to increase support.

Data on employed carers wellbeing was highlighted as an evidence gap during our challenge setting workshops and it was suggested that there was unpublished DWP data that could be made available.

> *How do you sell it to your employer? If you go and say ‘look I really want to keep my job but I’ve got my caring responsibilities, this is a plan I’ve come up which means I can still deliver what you need and I’m still here when you need me to be’, then you will get a far better response from your employer.*

Head of carers’ network (via interview)

Empowering employees

More needs to be done to empower working potential carers to understand the implications of their decisions. For example, taking a career break or opting for part-time work will have implications for their career and retirement.

It’s also important to support carers to become stronger advocates for themselves in the workplace. As discussed in the conversation support strand, guidance on how to speak a language that employers will respond to can make conversations more productive. This quote is one example of how reframing your ask as an action plan can land well with an employer.

Supporting Employers

Workplace policies & tools

Robust workplace policies and tools are crucial for working carers, and employers need to be helped to design them and implement them. This can really make it much easier for employers to embed them.

The Carer Passport has been pointed out by several people we've spoken to as an effective tool for supporting carers in the workplace.

Specifying the factors affecting whether carers stay in work was highlighted as an evidence gap during challenge setting workshops and would be important to understand to implement meaningful workplace policy. Additionally, it was raised that there is a need for more data and information specifically relating to the self-employed and SMEs.

> *A lot of employers and line managers are lazy and can lack courage. If you give them frameworks, options and ways of behaving, then it becomes a default - it means that they have to think about it less.*

Head of carers network (via interview)

Carer Passport

Funded by

Department of Health

Your guide

to Carer Passport schemes

In partnership:

carerpassport.uk

carersUK

carerstrust action·help·advice

Employment-specific user needs

Our research has identified these employment-specific user needs for both employees and employers.

As a potential carer, to make an informed decision about combining work and care, I need…

… to have awareness of caring and my employer's policies before needs emerge.

… to ideally feel that carers are valued in the workforce. Failing this, I need guidance to advocate my potential value.

… to understand the professional and financial implications of any decisions that I consider.

… an emotionally intelligent line manager to support my decision-making.

As a line manager, to support a potential carer to make an informed decision about combining work and care, I need…

… robust and clear company policies to give me the legitimacy to provide support.

… training and guidance to be more emotionally intelligent and nurture a culture of sharing amongst my team.

… guidance for identifying potential carers within my team.

Undeveloped & untested ideas

Ideas that were considered for this strand but not realised as prototypes or tested with users due to lack of time to engage the necessary stakeholders.

Workplace Culture

When including questions tailored for the identification of carers in anonymous employee satisfaction surveys, use language to connect with those who do not see themselves as carers and if participants do identify, create a signpost mechanism to connect with more information.

An email signature that carers can adopt to help raise awareness with colleagues.

Build statutory rights into existing childcare offers/support.

Focus on raising awareness/training amongst key professional groups as well as employers so there is a consistent offer.

Valuing carers:

Engage with influential advocates for supporting carers in the workforce to incentivise employers.

Providing support:

Develop guidance for employers to create a culture of sharing and support.

Empowering employees

Company-adapted checklists which quickly and clearly show what flexible working options are available to an employee to focus the conversation about needs and available support.

Advice for employers on the implications of their decisions. For all flexible working options, signpost to further information including video accounts from carers who have adopted the change, career and financial experts to advise on the potential implications and legal experts to remind of employment rights.

Create a template email for employees to send to HR/Employers, making it easy as possible for potential carers to engage their employers.

Write up a list of questions for employees to ask employers about company policy.

Workplace policies & tools:

Include in an employee’s contract a commitment to an annual review to support early identification of potential carers, and clearly state the support available for carers to remain in work.

Supporting Employers: Looking forward

What could be done next?

Consider which other strands in this report could be applicable to the employment space - for example podcasting and conversation support tools.

Work with key partners such as Employers for Carers (Carers UK) to co-design how advice and conversation support for employers and line managers can be made as usable in conversations as possible.

Convene a working group representing the diversity of employers to discuss how to incentivise supporting carers amongst the business community.

Interview a diverse range of businesses to better understand best practice for creating a workplace culture that is best suited to proactively identify potential carers.

Further questions to explore:

What is best practice for a potential carer supportive workplace culture? What does a culture of sharing look and feel like in practice?

How can we influence culture change across the system, from small to large enterprises?

How can advice be as accessible and usable as possible?

How can we better support working carers in their decision making for what options of combining work and care will be best for their situation?

5. Design Principles

Key findings that are broadly applicable across information sources

Design principles (1)

User need

Challenge / trade off

Utilise Touchpoints

Strategically utilise touchpoints that potential carers regularly encounter as a point of engagement (such as pharmacies).

Strategically deliver concise and accessible advice at opportune moments (such as waiting rooms) to support potential carer decision-making.

As a potential carer, I need to easily access key information to best advocate for my own needs.

Create more time for conversations about carer needs during healthcare appointments for people with care needs.

As a potential carer, I need space and time with professionals to make sense of my situation and understand my options.

Make it human

Promote real human contact as much as possible. Combining interventions with **in-person touch points** is more impactful.

Combine information with **multimedia accounts** from carers' real experiences (for example podcasts and videos).

As a potential carer, I need to hear from real experiences to help make sense of my own situation and feel less isolated.

Localise

Any nationwide initiative needs to offer mechanisms to signpost to more local information and services to be helpful. Coordinate closely with partners to make the best use of their resources and capacity.

Allow for localised adaptation of interventions to increase ownership and encourage adoption.

Permitting localised agency over messaging and touchpoints will encourage ownership but reduce centralised quality control.

As a potential carer, to make an informed decision, I need to access local support services as soon as possible.

Design principles (2)

User need

Challenge / trade off

Hybrid approach

Adopt a **hybrid approach** (a combination of digital engagement and human contact points e.g. phone/video calls) to cater to a variety of preferences for engagement, individual capabilities and busy schedules e.g. digital, automated, written, phone and in-person.

Making sense of a care situation can be overwhelming and challenging, so careful consideration needs to be given to how a potential carer are **guided through information and interactions** to ensure ongoing engagement.

As a potential carer, to make an informed decision, I need to be guided through information at a pace that is appropriate to my capabilities.

With limited time for decision making, how much can a potential carer's sensemaking be handled sensitively when urgency of action is vital?

Language and messaging:

Avoid using the language of care and caring to engage those who do not yet associate as carers **but acknowledge** the terminology in some way to **unlock the support and services** available.

As a potential carer, to make an informed decision, I need to be empowered to use the terminology of care to engage with support.

It is important to **represent** a **diversity** of care situations to reach as many people as possible.

As a potential carer, to make an informed decision, I need to hear from a diverse range of care experiences to make sense of my situation.

Information should be delivered in **digestible formats** as **task-focused and actionable.**

As a potential carer I need relevant information that is digestible and ends with task-focused suggestions of what to do next.

6. Community of practice

Value proposition, suggestions for areas of focus and future steps.

About the Community of Practice

Community of practice (CoP) refers to a group of people who share a common concern, a set of problems, or an interest in a topic and who come together to fulfil both individual and group goals. Communities of Practice often focus on sharing best practices and creating new knowledge to advance a domain of professional practice.

As the Care Choices project progresses, the CoP could serve as a helpful vehicle for gaining knowledge, feedback and expertise from a diverse group of academics, charity professionals, businesses and officials who are working in the sector. At the same time, the process of sharing information and experiences within the group enable members to learn from each other and develop their own or their organisation's approaches to care services, taking into account the latest evidence.

The importance of a Community of Practice

Throughout the project, we have been exploring and testing whether a CoP approach is a productive governance structure for this policy area.

Our engagement with the CoP has been positive and it has shown that a proactive group of experts from different fields can add significant value to policy and idea development. This is particularly true for the carers' sector, given its fragmentation, with a plethora of organisations, academics, informal groups and internal stakeholders. The existence of a CoP enables individuals from various parts of the ecosystem to come together to contribute in a time-limited but intensive manner and creates better alignment of efforts making for more meaningful change.

We see the CoP's key benefits to be:

- **Create new ideas** of policies and services as part of the Care Choices project and more broadly;
- **Prevent 'reinvention of the wheel'** by sharing best practices that already exist in the sector;
- **Provide instant feedback** on any new policies, services or ideas;
- **Support the formation of new partnerships and ensure a joined-up approach** on systemic issues such as the language and information-provision of caring

> *It might be interesting too to broaden it out in terms of, if we can raise one or two common issues we may have, for example the common care gap, and ensure we achieve consistent messaging about that across the group. It would be of huge value, in getting incremental improvements in terms of consistency of language and approach.*

Community of Practice member

Governance of a community of practice

The first stage of the Care Choices project aimed to energise and galvanise the existing group of practitioners and experts with the goal of ensuring the group continued to engage with DWP in the later stages of the project. During this stage, the group was very much facilitated by DWP and Policy Lab who organised, determined and led the activities.

For the CoP to be truly participant-led, **it is important to devolve and distribute authority and make sure participants play an active role in the running of the group**. A more collaborative governance method could motivate participants and ensure that the content is tailored to group members.

We ran a survey amongst the existing group members, which attracted eight responses. Four people said that they would be interested in contributing to a CoP newsletter, three volunteered to present to the group, one said that they would be interested in chairing a meeting and another participant expressed interest in leading a working group.

Although we had a small sample, **there is some evidence that group members are interested in taking a more active role within the CoP. This suggests that a community of practice could at least in part be led by member organisations.**

Engaging the CoP

Etienne Wenger, the educational theorist who initially outlined the concept of CoPs, suggested a seven-step approach to keeping CoPs engaged and effective.

1. Design the community to evolve naturally Encouraging new members and giving opportunities to different participants to take the lead could ensure the CoP grows and evolves organically and covers topics of its own choosing.

2. Create opportunities for open dialogue within and with outside perspectives
While the members and their knowledge are the CoP's most valuable resource, it is also beneficial to look outside of the CoP to understand the different possibilities for achieving their learning goals.

3. Welcome and allow different levels of participation
When surveyed, the existing members, expressed different degrees of interest in being engaged in the running of the group. Allowing participants to chair meetings, lead working groups or present to the group is important, whilst allowing for a more passive participation is also key.

4. Develop both public and private community spaces
Half the surveyed participants said that they would be interested in writing a newsletter for the rest of the group. Launching a newsletter - or considering alternative ways of utilising online tools, such as forums and mailing lists - could keep the group engaged beyond physical meetings.

5. Focus on the value of the community
CoP should create opportunities for participants to explicitly discuss the value and productivity of their participation in the group. Periodic surveys or open discussions could ensure that members have an opportunity to reflect on the added value of the group.

6. Combine familiarity and excitement
When surveying participants, all eight of them said that they liked interactive workshops as well as innovation, design thinking and prototyping. Promoting opportunities for the group to explore familiar topics in a different way can keep the group engaged and energised.

7. Find and nurture a regular rhythm for the community
When asked about the frequency of engagement, 5 out of 8 surveyed participants said that once a quarter would work best for them. Two said that they would like to meet once every two months, and one participant said that 2-3 times a year would be sufficient.

Risks and challenges

There are multiple challenges of running a CoP, some of which were flagged by participants themselves:

- **Membership challenge**: getting the membership right is key to making this CoP work. It is important to reflect on who else should be invited to the group to burst the bubble of ‘usual suspects’ and ensure diverse and relevant voices.

- **Sustainability challenge**: it can be difficult to keep a group engaged for a prolonged period of time, not least because some members of the group will inevitably leave. Having frequent meetings and regular communication is one key approach to mitigate the risk of this CoP breaking down.

- **Organisational challenge:** Catering for different levels of participation is important, however it’s challenging to coordinate the group and to delegate different responsibilities and tasks. Having a designated person to oversee the management of the group might be needed for it to run smoothly.

- **Knowledge management challenge:** It is important to establish the system for capturing, disseminating and storing intel from this CoP and ensuring it is built into government services and policies.

> *In principle a forum which wrestles with some of this stuff is a good thing. Problem is people change and move on, have different areas of responsibility – and in some sense you always need to keep the work fresh and live, if only that everyone has it in their sights.*

Community of Practice member

Areas of focus

We asked the group about their vision for future phases of a CoP. Some of their suggestions included:

- Carrying on the existing work on finding solutions for addressing information provision for potential carers:
  - “Seeing solutions from the initial three workshops delivered, promoted and embedded”
  - “It would be good to update on ideas discussed at the workshop on 31 March 2022, e.g. testing, proposed next steps, etc.”
  - “Putting some ideas into practice to test them out further. These could include, for example, testing a new communication about getting financial information and support if you are working and caring (e.g. about potential costs of arranging care in the home or residential care). And/or, for example, testing a new route such as using a specific consumer channel, or trade association, to reach people who are working and caring.”
  - “Reviewing progress of the implementation of the work.”
  - “[Inviting] feedback from potential carers and evaluation of any potential carer initiatives that are introduced.”

- Exploring availability and visibility of information, or signposting information;

- Mapping the system, capabilities of the stakeholders and opportunities for intervention / change;

- Bringing together "carer-facing" activities with "organisation/profession-facing" initiatives to form a holistic and collaborative approach backed by data that is capable of recognising and underpinning improvement grounded in the perspective of potential carers;

- Learning from research and evaluations and exploring how it can inform policy and practice.

Future steps

In light of our engagement with the Community of Practice throughout the project and what we heard from the Community of Practice members themselves, the following steps could be considered in any future activity:

- **Promoting engagement and participation:** Communities of Practice are evolving and living entities, and it is vital that they are continuously engaged and motivated. Approaches that can be helpful for keeping a group active and engaged include: providing effective facilitation and considering techniques for encouraging active involvement; holding meetings regularly (without prolonged pauses); forming working sub-groups; delegating specific tasks (such as chairing meetings); exploring the option of online / email engagement between meetings; and inviting external speakers.

- **Utilising collective knowledge and experience:** We have experienced the power of *collective intelligence* held within the Community of Practice. It is important to explore different ways for utilising a group's wealth of experience to inform the next steps of any policy / service decisions. Circulating surveys, using the meetings for testing ideas and seeking direct suggestions for suitable contacts are just some of the potential approaches for making the most of the group's knowledge and experience.

- **Promoting joint approaches and common language:** Our work illustrates that the current information and service landscape is highly fragmented. Using the Community of Practice for agreeing on common approaches and language could streamline carers' navigation of the system. For instance, organising sessions focusing on different organisations' best practices or having specific working groups to delve into certain issues could help promote common approaches across the board.

- **Capture learnings:** We have observed that Communities of Practice change rapidly - people leave organisations, new services pop up and the focus shifts. It will be therefore important to explore different mechanisms for effectively capturing the learnings of the group. Keeping a shared online folder for all members, recording sessions, circulating short meeting minutes and keeping a database of best practices could help ensure that knowledge is shared effectively.

7. Annex: Evidence cards

The following slides display evidence cards used during challenge setting workshops in 2022. They were built from evidence about the care information problem at that time. As such, some statistics quoted in the present tense may be inaccurate or out of date.

You can read DWP's report discussing the evidence base in greater detail in a report titled *Supporting working people to make informed decisions about work and care* which can be found on the following webpage: Carers' Employment Digital Discovery and Care Choices reports.

Some evidence cards include findings derived from qualitative research with carers conducted for DWP by Ipsos in 2018, available via the following link: Qualitative research with working people exploring decisions about work and care.

Potential carer persona

45-SPa

People **aged 18 and above**, with a particular focus on those aged around **45 to State Pension Age (SPa)** who are **currently in work** and facing decisions about work and care.

Those who are making **initial decisions** about their role in **meeting someone else's care**, including whether or not to **provide care themselves**, and how to **combine work and care**.

People who are facing decisions about their role in meeting the **care needs of another adult** (e.g., a parent, partner or adult child) rather than those who are caring for a disabled child aged under 18.

Specifically **working people in England**, recognising the fact that many of the relevant policy areas are devolved and as a result the services and support available for carers may differ significantly.

There is **no such thing as a 'primary potential carer'** in the way that there might be a 'primary carer'. There are only **a range of potential carers** in different circumstances **all facing decisions** about what course of action best balances their needs with those of the cared-for and other potential carers.

Two thirds (65%) of UK adults had provided informal care at some point between 1991 and 2018. This proportion rises to **seven in ten (70%) for women**.

½

Around **half of adult carers** combine care with either full or part-time work (49% of female and 52% of male carers).

x8

Women are almost **eight times more likely** to become **economically inactive** in order to care for their home and family, and are at **greatest risk of dropping out of work to care** between the ages of **40 and 64**.

£

Even if people don't give up work altogether, they often reduce their hours which can **substantially limit wage progression**, or turn down opportunities for promotion in order to accommodate their caring activities.

These cards are design artefacts used in 2022 and their content may be out of date.

Identifying as a carer

Most information and support is **targeted at 'carers'**. Many people providing care however, often **don't think of themselves as carers**, meaning that support aimed at carers can be **invisible** to them.

91% of carers said they **missed out** on financial or practical support (or both) as a result of **not identifying as a carer** (Carers UK, 2016).

Carers UK (2016) has found that the majority of "carers" take **years** to own the term.

People unfamiliar with what caring entails may not recognise their situation as one that presents decisions which can be supported by information.

"I didn't see myself as a carer, so it's almost impossible to look for things to help you with your situation."

Female, London Focus Group, Ipsos MORI research

'Care' can be assumed to apply to **professional or paid carers** or include only certain activities such as **physical care**, rather than others such as shopping, managing finances from a distance, or providing company and emotional support.

Outreach workers working with **black and ethnic minority communities** have found that the **unfamiliarity** of both the **word and the concept of "carer"** has presented particular difficulties for local initiatives aimed at supporting minority carers (Griffiths, 1992)

daughter, son, wife, husband...

Potential carers report that they see themselves as **'looking after a family member/friend'** rather than 'caring' or being a 'carer'.

"When people say to me, "You're his carer", I say, "No, I'm not, I'm his wife." … We married because we loved each other … He would do a lot more for me if he could, I know he would"

Female, London Focus Group, Ipsos MORI research

These cards are design artefacts used in 2022 and their content may be out of date.

Capabilities, mindsets and emotions

Some potential carers understandably report being **reluctant to find out** their friend or relative's full prognosis or likely trajectory of their care needs.

Focus on the cared-for's **urgent needs** can **prevent** people from considering their own, or from seeing their situation as **one with choices available.**

Feelings of **guilt** when considering personal needs and values alongside the needs of the cared-for is a commonly reported experience among carers.

Information that **acknowledges the challenges** of caring and **encourages** people to **factor their personal needs** into decisions may help alleviate feelings of guilt.

Being proactive is challenging, and some do not seek support **until crisis hits.**

Prolonged stress causes **burnout**, adversely affecting decision-making

Lack of digital capability - 11.9m people in the UK (**22% of the UK population**) lacked basic digital skills, such as the ability to open web browsers and find internet pages.

Family members and friends often **willingly make sacrifices** to help. They can feel it is their **duty** to do what they can and that they have no choice but to begin providing care.

Decisions are **complex, emotive** and can involve **choosing between deeply-held values** that will often require **trade-offs.**

These cards are design artefacts used in 2022 and their content may be out of date.

Circumstance and social connections

Time pressure can limit ability and motivation to explore options. Existing commitments (such as paid work or child care) limits capacity to explore options and consider long term implications

Potential carers with more money may be more willing to **take time off** work or consider **paying for support** to manage work and care, but this can also be a **barrier to seeking info about state-funded support.**

Care roles

Roles such as that of a 'primary carer' can **fix perceptions** of whose 'responsibility' the care is and prevent more sustainable, shared arrangements being sought.

> ***"I feel frustrated. Because she lives close to me, I'm the default carer, seven days a week. There wasn't a proper discussion about sharing the load."***
>
> Male, Nottingham interview, Ipsos MORI research

Work situation

Workplaces vary greatly in **how flexibly** people are able to work and in how effectively employers support potential carers.

In 2015, **only a third** of employers (34%) had a formal, written policy or an informal, verbal policy in place to support carers in their workplace.

Rigid job structures limiting the **ability to adapt** where, when and how staff work can make **fitting work schedules with care** especially challenging.

A **supportive** line manager, colleagues, carer networks and HR policies can act as important **touchpoints signposting** to helpful information.

Fear of repercussions from taking time away from work or being viewed as less reliable due to personal commitments can be a **barrier to these constructive conversations** between managers and staff.

These cards are design artefacts used in 2022 and their content may be out of date.

Development and urgency of care needs

When a diagnosis is **terminal**, spending what remaining time you have with the care-recipient can become first **priority**, **side-lining** other considerations.

Thinking long term can also be particularly challenging if care needs **emerge suddenly**, or if a condition's prognosis is **uncertain**

> ***"I've just been putting out each fire as it lights up. I haven't had time to think that far into the future about help."***
>
> Female, Nottingham interview, Ipsos MORI interview

When the onset of care needs is **sudden**, relatives and friends may be **more likely to mobilise support collaboratively** in response to a clear emergency and then **remain involved over the long-term, sharing care** activities between them.

In cases of more **gradually increasing needs**, participants more often reported that they felt the division of care among family was **imbalanced**. Needs can **slowly increase**, ratcheting-up demands on time and energy **without prompting** individuals to seek help from others until it is too late

Cultural

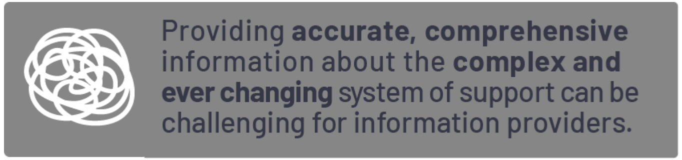
Social norms around taking on care activities are stronger for women and can be more prescriptive within some communities than others.

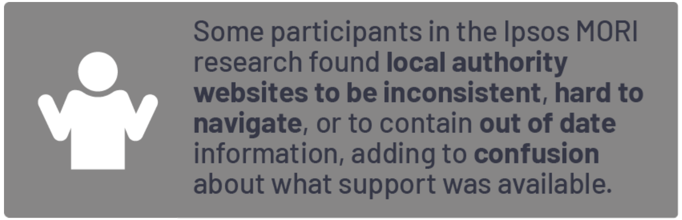
Deep-seated, historical and cultural expectations about where 'responsibility' lies within society or families to provide care may be continuing to influence decisions.

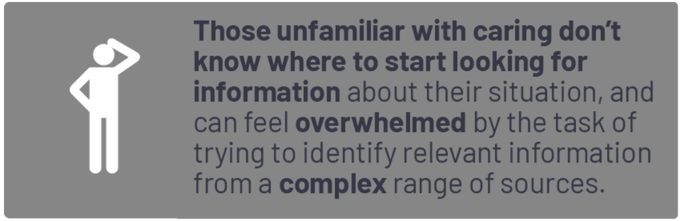
Norms are often transmitted and reinforced through information.

These evidence cards are design artefacts used in 2022 and their content may be out of date.

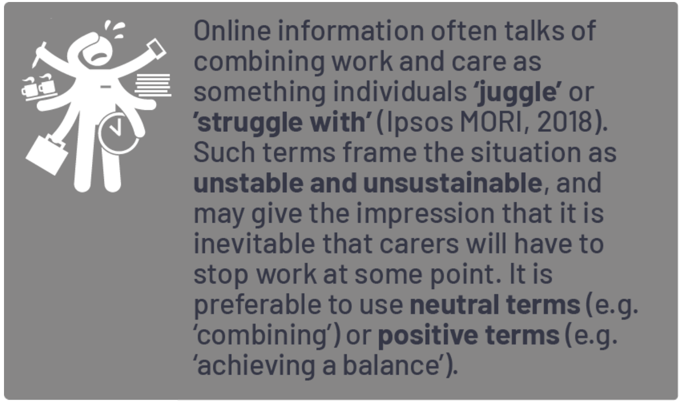
The scale and complexity of the social care system

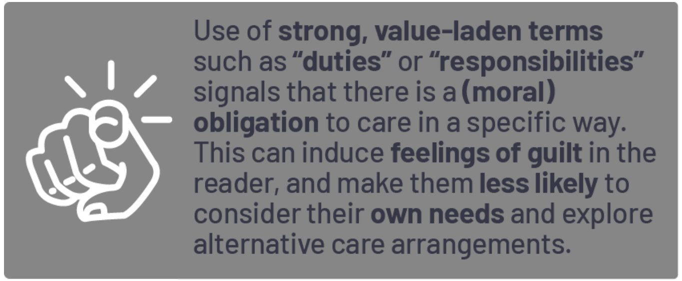

Providing **accurate, comprehensive** information about the **complex and ever changing** system of support can be challenging for information providers.

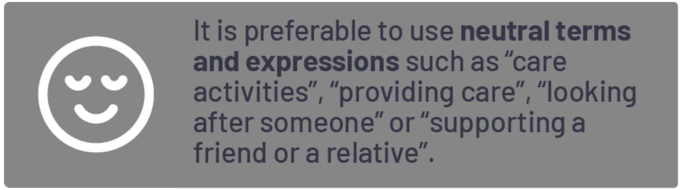

Some participants in the Ipsos MORI research found **local authority websites to be inconsistent**, **hard to navigate**, or to contain **out of date** information, adding to **confusion** about what support was available.


Those unfamiliar with caring don't know where to start looking for information about their situation, and can feel **overwhelmed** by the task of trying to identify relevant information from a **complex** range of sources.

The use of language


Online information often talks of combining work and care as something individuals **'juggle'** or **'struggle with'** (Ipsos MORI, 2018). Such terms frame the situation as **unstable and unsustainable**, and may give the impression that it is inevitable that carers will have to stop work at some point. It is preferable to use **neutral terms** (e.g. 'combining') or **positive terms** (e.g. 'achieving a balance').


Use of **strong, value-laden terms** such as **"duties"** or **"responsibilities"** signals that there is a **(moral) obligation** to care in a specific way. This can induce **feelings of guilt** in the reader, and make them **less likely** to consider their **own needs** and explore alternative care arrangements.


It is preferable to use **neutral terms and expressions** such as "care activities", "providing care", "looking after someone" or "supporting a friend or a relative".

These cards are design artefacts used in 2022 and their content may be out of date.

The framing of choices

When information has been designed primarily for **already established carers**, without considering the distinct needs and options available to **potential carers**, this can **narrow the range of options** a potential carer believes they have available to them.

Much information assumes a **'primary carer' model** of care, (where one person takes on the majority of care activities) and does not present options still open to people at early stages of their journey (for example, self-funded care or discussing options with family and friends).

"I can remember so many of the conversations [with the GP] were about my mother's condition. Looking back, there wasn't nearly enough focus on who was going to be providing the care for her."

Female, Nottingham interview, Ipsos MORI research

Discussion on **sharing care** with friends and family or formal services is **often limited** and frames these options as ways to temporarily relieve the burden of the primary carer role.

These cards are design artefacts used in 2022 and their content may be out of date.