



THE UNIVERSITY
of EDINBURGH



Informal Networks of Care

JANUARY 2024 CARETREE STUDY REPORT

Thank you

Dear Contributors,

We want to express our heartfelt gratitude to those involved in the CareTree project. Your contribution has been invaluable, and we appreciate your time and dedication.

We are excited to provide you with an update on our progress so far. With your help, we have successfully completed data collection and are now analysing the gathered information. Your insights have greatly enriched our research.

Thank you for committing to this project. Your active participation has made our research possible and has played a vital role in the research outcome. We will continue to ensure the utmost confidentiality and privacy throughout the research process.

Once again, we sincerely thank you for your support. We look forward to sharing the final outcomes with you soon.

Best regards,

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Research Summary

The Enhancing Informal Networks of Care research project is part of the Advanced Care Research Centre (ACRC). The ACRC is a multi-disciplinary research programme with the aim of generating high-quality, data-driven, personalised, and affordable care that supports the independence, dignity, and quality of life of people in later life. The CareTree study project sits within the 'Understanding the Person in Context' initiative of the ACRC that utilises innovative qualitative methods to understand better how individuals and their families experience later life and care.

RESEARCH AIMS

The aim of the Enhancing Informal Networks of Care project is to better understand the role of informal care in supporting older adults, towards realising ways to reinforce these networks. Recognising how hidden and often undervalued informal care is, we intended to realise the value of such care and make it more visible within our society. By engaging and collaborating with older adults, this work has sought to capture their present challenges and re-imagine their care futures. Given this scope, the research consists of two main areas:

1. Capturing the value of informal care in later life, and understanding the role of care network in supporting ageing in place.
2. Developing corresponding tools to support communities and designers to better navigate and explore our care futures.

RESEARCH ACTIVITIES

To complete these aims, we conducted the following research activity:

- **Cultural Probe:**
First, we have developed a tangible, tree-shaped exploratory activity that was placed in the homes of older adults for a month. By providing daily prompts for participants to reflect on, the study captured instances and notions of care in their lives. Participants were later interviewed on their responses.



Understanding Networks of Care

Find out more about the study into how older adults perceive the informal networks of care which support them in everyday life.

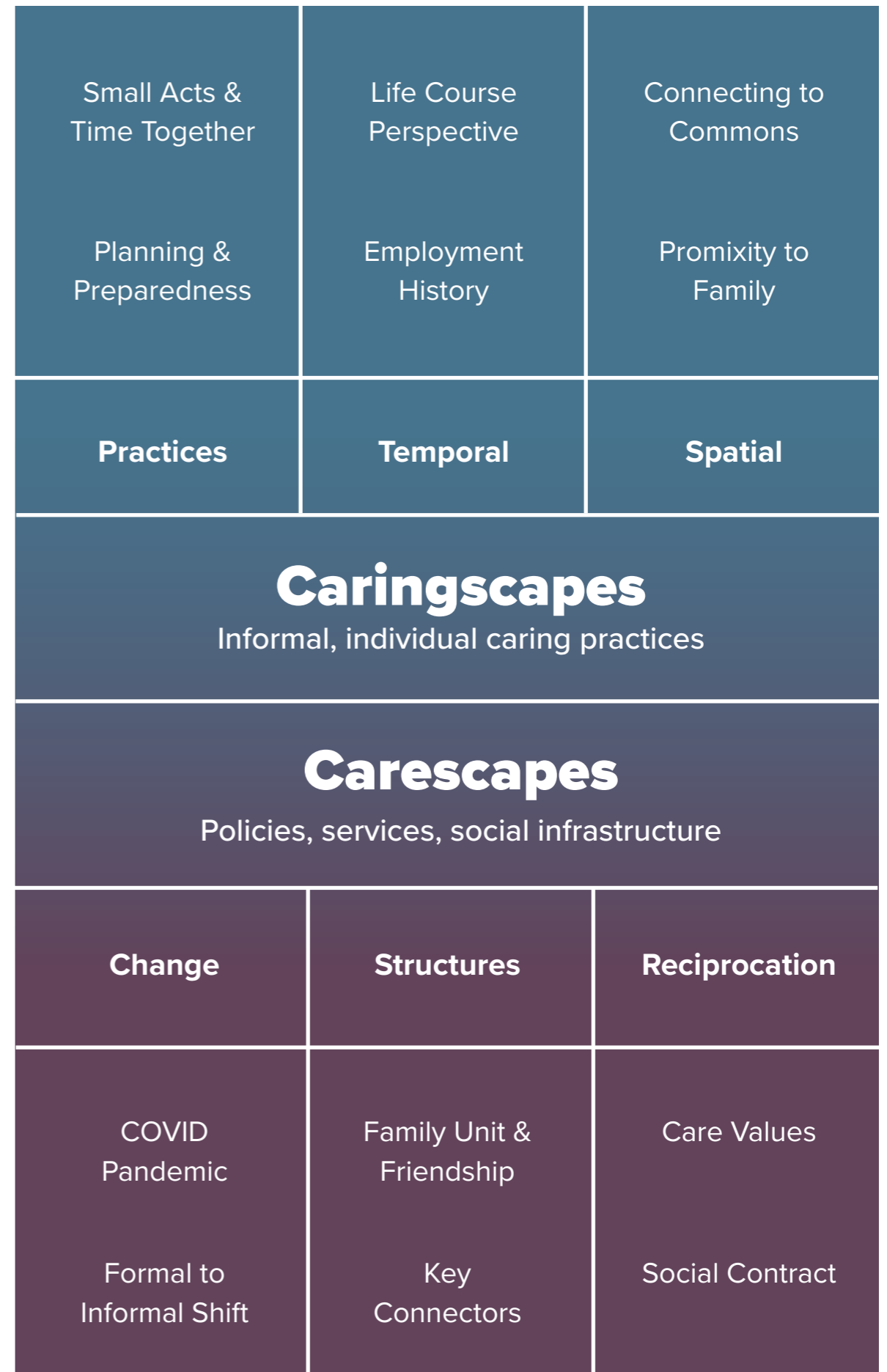
With a growing reliance on family and friends to provide care and support their ageing in place, the informal care networks of older adults are an understudied yet vital to their long-term wellbeing. To understand this “landscape” of caring relationships and interactions, we sent 18 older adults from across Scotland a CareTree cultural probe kit to capture instances of care in their lives. The diagram on the right demonstrates the thematic framework for informal care which we used for analysis¹.

Overall, the findings highlight how individual care practices intersect with wider shifts and trends, illustrating what is seen as meaningful, gaps around learning to care, and the importance of proximity to key connectors like family and friends. Regarding individual acts and contexts of caring, known as ‘caringscapes’, we found perceptions of quality of care are often contingent on proximity to family, with communal spaces and meaningful places of high importance, while the timeliness of care and preparedness of those around you for caring roles also detailed. Meanwhile the

intersections between care policies, services, and infrastructure, known as carescapes, highlighted the changes participants had experienced through the pandemic and long-term NHS under-resourcing, revealing issues of social isolation and mental health. These changes provided challenges to the plans and values participants had, as well as a growing reliance on informal networks for family and friends. Many saw how these networks were built on reciprocal caring and social values they felt were eroding.

This research serves as an essential framework for the following workshop series, which seeks to create a corresponding infrastructure that further supports and enhances these networks of care. By highlighting the growing importance and reliance on families, friends, and support groups in supporting ageing in place, we can explore ways of developing more resilient and sustainable forms of everyday care that draw on local communities and knowledge.

¹Bowlby S, McKie L. Care and caring: An ecological framework. Area. 2019; 51: 532–539. <https://doi.org/10.1111/area.12511>



Hearing from our participants...

Caringscapes

On acts of kindness:

“I didn’t realise that would come under caring, I never thought about it as coming under caring... helping somebody up out of their chair the other, that was caring.”

On leading by example:

“Just say hello to people when you’re passing and things like that, they’re not going to think you’re a weirdo or anything, just say hello, it’s something for the next generation, I think would help, they’re the next future”.

On-time together:

“Time is a great thing for people. Everybody is in a rush nowadays. They are all going from here, there, have got appointments, got to go here. Sometimes just to give a lot of time, an hour, to say, come on we will do this, come on we will do that or just some activity even that somebody likes. But I think time is a great thing but we have not got it now. It is dwindling.”

On prioritising time:

“When I worked in the care sector, you know, I loved my job, but you didn’t have the time because you never had enough staff, so, therefore, you had to hurry to the next one if you like. So, it would have been lovely if you could have had time, a lot more time to give them a wee bit more personal time, you know what I mean?”

Giving & receiving care over time:

“It’s my time now; I’ve done my bit of caring. And I’m not saying that it just stops because there always will be that care available for my family and my friends”.

On preparedness:

“you’re prepared for having children... whereas they don’t prepare you for getting old; you just have to get on with it”.

On access to care services:

“They’ve shut all the hospitals. You know, just everything. No there’s something seriously... and you run the NHS as a business, but it’s not going to work ever. So, I don’t think...and I just think it’s detached from the reality of what’s going on.”

On informal and formal care:

“informal care is great if it’s bolstered by family giving some informal. The formal care from the council or from a private agency for essential tasks only, the person comes in, they whisk in, they do what’s to be done, and they whisk out... that’s fine when the person that they’re coming in, they’ve got family... but when somebody’s to depend on formal only that’s when it’s really quite sad because it’s not enough to have a quality or a standard because it’s only basic.”

Carescapes

On underfunding support:

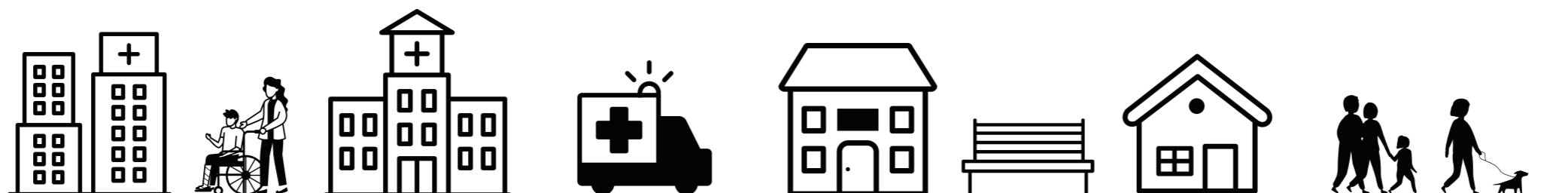
“I think groups can make a big difference. But often, the way they do things, like with funding, they have to bid for funding or something. You know, they maybe get funding for a project, so they’ve got something for so long, you know, whereas some of these things could be doing with much more long term, you know.”

On changing norms:

“One of the benefits I think of COVID was I joined an online...a Facebook group. You know, a kind of neighbourhood Facebook group and people were volunteering to collect prescriptions and do the shopping and helping out during COVID.”

On community values:

“You had a social contract, which a lot of people had in the past, because their neighbourhoods, you grew up, as I say, the neighbours...looked out for one another, and they shared things”.



What's next?

This overview provides a number of findings and insights, that scholars, designers, and policymakers can take away. As we have portrayed, at the intersection of individual care practices and broader care infrastructure remains an emergent, contested and messy carescape. Towards engaging this context, we see the following as key considerations for those seeking to support and enhance informal care in later life:

- We need a broader refocus on the space between individual practices and broader societal changes within the context of later life. As we have recognized, the goals of older adults to age in place are shaping policy and economies at scale, but the pandemic and ongoing austerity have also influenced a growing burden on informal care.
- Further, the growing friction between older adult's care values and their communities' preparedness to care illustrates the many barriers we face in realising 'desirable' ageing and care and the potential benefits of a relational approach to our caring futures.

- Finally, in recognising the changing attitudes, practices, and forms of informal care in later life, we should consider how the 'care rift', not unlike the digital divide, is leaving older adults behind, with ambiguity and concern for the future that stops efforts to plan or develop the structures necessary to successful ageing.

With these findings, we seek to share our insights, and build from them, with the communities of individuals who have participated. Following workshops will share key themes and seek to unpack their meaning and importance within the group setting. In doing so, we seek to spur thoughts around building resilient and sustainable informal care practices through community infrastructure. We plan of conducting these over February, March, and April, 2024.

- **Dundee Workshops:** Three workshops will be run with a local seniors group.
- **Greenock Workshops:** Three workshops will be run with a local arts centre

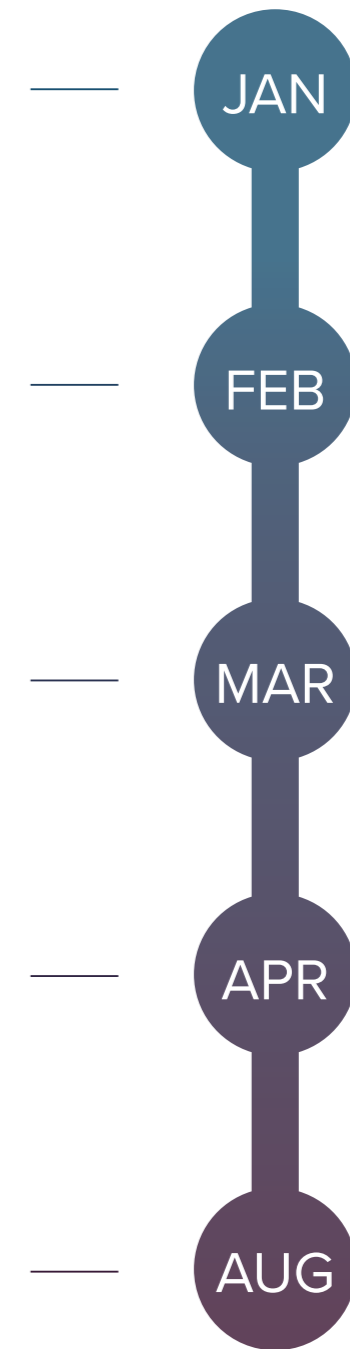
• Submit findings to a Design conference.

• Share results as a report for participants and communities
• Unpack the findings with interested groups.

• Explore potential new infrastructure with local groups.

• Collaborate with groups to build corresponding resources and enable advocacy

• Report on collaborations
• Present & Publish on Project





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