

# Catalonia and Scotland: PATHS TOWARDS THE RIGHT TO CARE

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On **16th December 2023**, the Catalan **Right to Care Network** together with **The School of Innovation and Technology in Glasgow School of Art** held an **“International Exchange on the Right to Care”**. The aim was to foster learning and sharing of experiences between Catalonia and Scotland as both embark on a journey towards ensuring **a rights based approach to care** in the development of their respective national care systems.

The event — attended by a wide range of participants from civil society, public sector and government, independent sector, third sector and academia — was designed and facilitated by the Glasgow School of Art with the Right to Care Network.

Speakers from Scotland included: Karen Hedge from Scottish Care (a national membership organisation and the representative body for independent social care services), Irene Oldfather from the Health and Social Care Alliance Scotland (known as the ALLIANCE, national third sector intermediary for health and social care), and Craig Morris from the Care Inspectorate (national official body responsible for ensuring and promoting the quality of care). Speakers from Catalonia included: Amelia Campos from Més Que Cures (a self-organised work and care provision organisation in the Poble Sec neighbourhood of Barcelona), Carmen Lorenzo from La Colla Cuidadora (a community initiative dedicated to supporting family carers), and Maria Herrero Canela from Sindicat de Mares en la Diversitat Funcional (a collective of mothers of children with functional diversity), and Dolors Comas from the Right to Care Network.



# A brief context: Dialogue between Catalonia and Scotland

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Catalonia, as an autonomous region in Spain, and Scotland, as a devolved nation within the United Kingdom have the parliamentary powers to make policies and decisions around health and care, and they share a similar aspiration to serve the interests of their citizens by enabling engagement and bringing decision making closer to the communities that they serve. **One key area of common interest is the collective responsibility towards person-centred, human rights based and relational approaches to care.** Both territories also face a range of demographic challenges related to ageing populations, declining birth rates and changing family structures. These factors, coupled with the impact of Covid-19 and the current global socio-economic context have brought to the fore the critical inadequacies of the existing hegemonic models of care, and highlighted the urgency in addressing these as part of the social and political agenda in each context.

**In 2021, following an Independent Review of Adult Social Care which outlined significant challenges in the**

**Scottish social care system, the Scottish Government proposed the creation of a new system called the National Care Service (NCS).**

The aim is to improve community health and social care provision by creating comprehensive support for people of all ages and with diverse health and care needs, including better support for unpaid carers, and to ensure that care workers are respected and valued. **In 2022, a Bill was launched** providing the framework for reform of current provision and the creation of the NCS and making a commitment to placing human rights at the heart of services.

**The process of building the NCS in Scotland, however, is not a path without challenges.**

The acceleration of this transformation has accentuated the **many tensions**

between policy and practice especially raising concerns for caregivers and care workers, due to a lack of clarity on how the proposed changes impact on national vs. local models of delivery, workforce capacity, and integration of health and social care services already underway. It has also been noted that the Government's stated aspiration on centering lived experiences and co-designing the NCS with citizens has not been reflected in its actions. Thus, in 2023, it was decided to extend the timescales for Stage 1 of the Bill, and the Government has used this time to undertake further engagement with people with lived experience, workforce, and caregivers through NCS forums online and in-person.

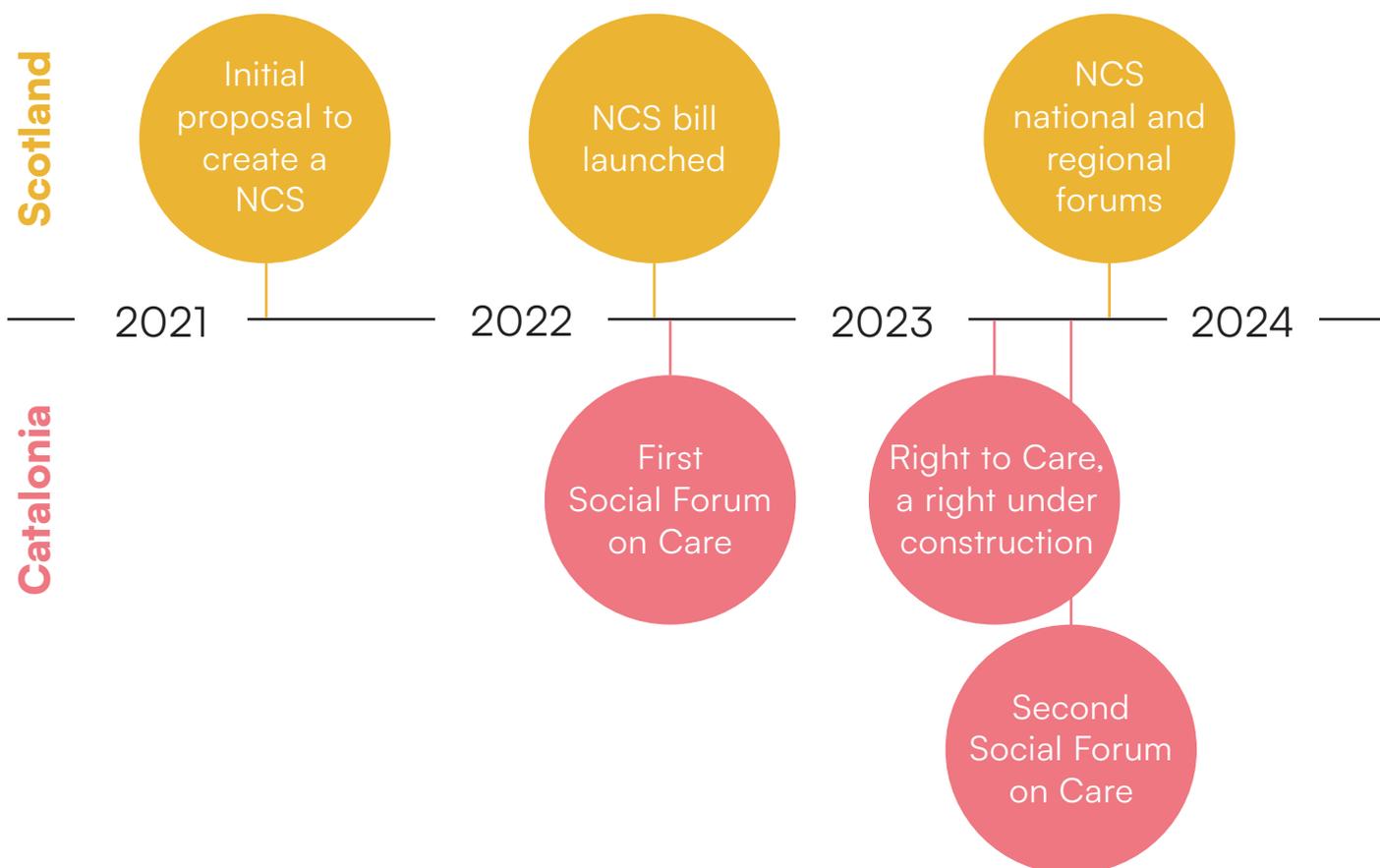
## **In Catalonia, the government has been initiating various top-down actions to transform care in the past few years.**

This includes: improving dependency services (e.g. nursing homes, home care), training family carers, introducing policies to protect citizens' time for caregiving and provide equity in care work, as well as notably in 2023 starting to formulate a National Strategy for Integrated Social and Health Care.

## **The real impetus for transforming the care experience, however, arose in 2021 from a social movement advocating for transformative and feminist care. This became the Right to Care movement led by a group of activists, academics, organisations and social groups.**

It was a response to the existing structural deficiencies in the Catalan model of care that had been recently further exposed by the Covid-19 pandemic; the heavy reliance upon family structures to support care and disproportionate negative impact on women, non-nationals and those from underprivileged socio-economic backgrounds who are dedicated to caregiving.

The movement organised the **First Social Forum on Care in March 2022**, mobilising over 350 people and 100 organisations to collectively construct a participatory space in which to understand more deeply the lived experiences of people throughout the life course- from birth to death, as well as in specific moments of care.

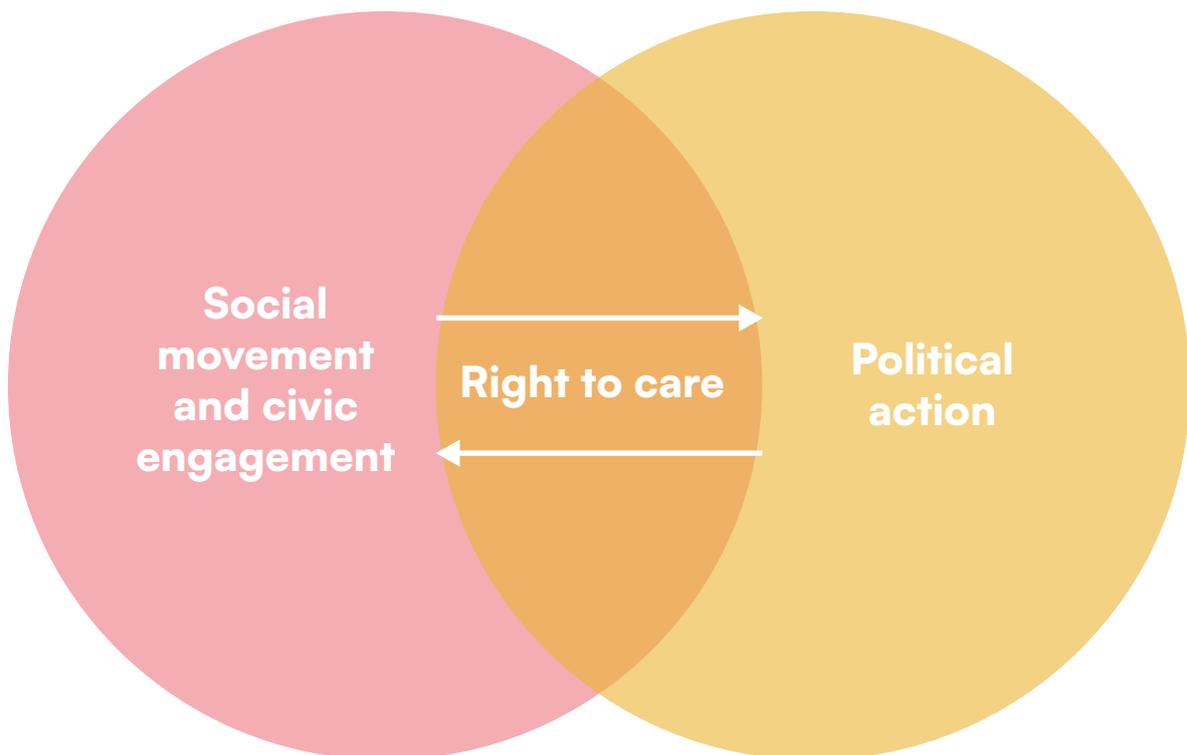


The aim is to help **shape a model for a Caring Society that integrates the various social, educational and health dimensions of people's care needs over a lifetime**. The Forum proposed a community-based approach, one that is driven by the active engagement of all interested stakeholders: those in care, affected by care or in charge of it. The event culminated in the co-creation of a Manifesto for the Right to Care and one month later, the establishment of the Network for the Right to Care. The movement's demand to the Catalan government to define a new National System of Care involved subsequent parliamentary audience and a set of four decentralised Forum events across the territory in 2023.

In parallel, some local councils such as those of the municipalities of Alella or Tiana who form part of the Villages that Care ('Pobles que cuiden') network, and supra-municipal administrations such as the Provincial Government of Barcelona are progressing the conceptualisation and deployment of the Caring Municipality ('Municipi Cuidador') strategy.

Key to both the Scottish and Catalan endeavours are the need for political processes of systemic transformation to work in tandem with dynamic processes of participation and co-design with civil society; thus enabling diverse experiences and voices of those receiving and delivering care to jointly define and shape what the right to care would look and feel like for people and communities.

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# A starting point: Collectively identifying needs

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Although the steps taken to date in Scotland and Catalonia to establish national systems of care vary, we recognised common frustrations and hopes, as well as opportunities to **learn from one another about what it takes to drive a movement to structurally redefine Care placing human rights at the heart of service provision.**

This International Exchange aimed to **establish dialogue and initiate a sharing and learning platform** to link Scotland and Catalonia as we work towards reforming our systems of care through initiating a series of engagements and collaborative activities.

**On 16th December, we specifically focused on how the voices of those involved in providing care can be integrated in the co-design of national care systems to ensure they meet the needs of those providing and receiving care.**

Synergies and learnings from experiences of those providing care in Catalonia and Scotland, and key focus areas for future work have been identified and summarised in the following pages.

# The diverse vulnerabilities, concerns and needs of different carers must be understood and made visible.

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Speakers from both contexts highlighted that **caregivers, professionals and family members are much older and more diverse** than normally depicted.

Karen Hedge noted that the average age of unpaid carers - women with kinship ties - is over 70 years. Amelia Campos shared that the average age of care workers in Spain is 54 years. Both emphasised the urgency of taking such aspects into account in the design of care policies, emphasising the need to adapt them to specific contexts.

Campos also highlighted the urgency of **addressing the poor working conditions of care workers** in a highly feminised and racialised sector. For example, in Catalonia, although the average working day is 23 hours per week, 1 in 10 female carers work more than 60 hours and with an average remuneration of €5 an hour, well under the living wage. Moreover, it is estimated that 30% of carers work in irregular and informal job roles, thus, highlighting the need to make visible the hidden economy of care.

Karen Hedge shared an example where, in one of the areas in Scotland an increase in remuneration aimed at attracting more people to join the care work force surprisingly resulted in more men joining or expressing interest in care work, thus, drawing further attention to **gender dynamics and pay** in the care sector.

Maria Herrero Canela criticised a further **lack of data on and the invisibility of the groups** of mothers who care for young children and adults with long term disabilities, which leads to the violation of their rights and those of their children. According to the Union's data, she noted there are around 3,000 such carers in Catalonia, of which 100 live in the city of Barcelona. Policies and allocation of resources, thus, need to be tailored to suit the diverse needs of different groups.



# Self organised groups and peer networks play an important role in enabling mutual support and empowering carers.

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Prolonged and intensive care experiences have a significant impact on the lives of caregivers, who in many cases experience a decline in their own health and wellbeing because of increasing demands on their time and a lack of recognition of their economic and social rights. The **healing and empowering effect of creating connections and networks** was emphasised by speakers in both contexts.

Karen Hedge highlighted the **positive impact of networks in the fight against isolation**: “networks become a vital tool in dealing with this feeling of loneliness, offering support that counteracts the invisibility inherent in our work.” She also noted the **importance of human connections in care**, adding that technology can play an enabling role here by supporting management of everyday tasks and, thus, creating more time for caregivers to focus on ‘caring’.

Amelia Campos highlighted the **importance of self-organisation projects**, pointing out the empowering effect on the community. These projects **promote mutual support and exchange of knowledge** among individuals and initiatives. Additionally, she emphasised the key aspects of formalising citizenship status and the professionalisation of workers within the agenda of such initiatives, in a sector predominantly led by women, mostly of non-EU origin. A set of initiatives with the dual function of union advocacy and labour self-organisation, she noted, was key to **promoting the dignification of working conditions and remuneration**.

Carmen Lorenzo spoke about her belonging to a community support group, highlighting how the La Colla Cuidadora has allowed them to **share emotions, worries, difficulties and thoughts, and to receive and offer emotional support and companionship**. She also added that the social and health services were involved, providing information and access to resources to the group. Thus, the group “counteracts the difficulties experienced by relatives of people with Alzheimer’s or dementia, providing a safe and welcoming space in which to train, socialise and find comfort”. She also shared how the carers in the group not only look after their relatives, but **look after each other**— thus, also learning to look after themselves and let themselves be looked after. We were reminded that at some point in our lives we will all need to be cared for or will have to care for someone, and that by making care visible we contribute to a better understanding of what caring for someone implies, and ensure that people become involved in it. That is why the La Colla Cuidadora actively participates in the Right to Care Network, to help give visibility to caregivers, and to contribute to **improving the quality of care for caregivers and cared-for people**.

# Enough time and appropriate spaces are needed to enable participation and design of person-centred care policies.

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Experiences shared by all speakers highlighted that it becomes difficult, if not impossible, for both paid and unpaid carers to be able to participate in co-design processes, as **caring is so intensive and time consuming**, particularly when the economic and social support available to them is so scarce.

Maria Herrero added that **participation is not possible if decent living conditions are not ensured for all caregivers**. Herrero's statements highlighted the difficulties faced by the group of caregivers in mobilising and the need to turn the discomfort derived from an intensive care relationship into creative and transformative energy to organise and fight for their rights. "The nurses are doing it now", she said, referring to the nurses strike that took place in Catalonia in December 2023, further adding — "but [carers] don't block the streets, because maybe we don't think we have the right to."

Irene Oldfather shared the story behind and the **importance of the Charter of Human Rights** that was created in Scotland to ensure that the rights of people with dementia and their carers are fully recognised, by embedding the PANEL principles:



She highlighted the way in which the charter was **drawn up through a participatory process** facilitated by members of a Cross Parliamentary Group on Alzheimers, Scottish Human Rights Commission and Alzheimer Scotland. She shared that to develop the charter, "we asked people about their experience in care and it was a story of loss. Loss of independence, treated like a child, not listened to. So what we have tried to do is create programmes around what people have told us about living in old age and with dementia." She also emphasised the **importance of effective implementation and monitoring of policies** to understand their impact on different people and groups: "are we reaching those who need it?".

# Participatory models integrating lived experience expertise is important for innovation, evaluation and improvement of care systems.

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Craig Morris and Dolors Comas shared examples of ongoing work towards the improvement and innovation of care in each context of Scotland and Catalunya.

Craig Morris shared that in addition to the independent review of adult social care undertaken in 2021, there have been **a number of ongoing activities to improve care in Scotland**, including — an independent review of Inspection, Scrutiny and Regulation, development of an improvement framework for social care and social work, and review of mental health scrutiny and assurance. He highlighted the **need for willingness to listen and integrate the voices of people involved in care**, taking into account their needs, experiences and age as key to these processes. Through initiatives such as the development of an annual participation plan and ‘The Promise’ project working with children and young people (including those who have care experience), he highlighted the **importance of methodological efforts and the diversification of participation formats** to enable those with lived experience to contribute to proposals for improvement and innovation.

When asked about enablers and barriers for change, he noted that the various review processes (mentioned above) have collectively generated **over 70 recommendations, which provide a path forward to improve care and inform the systemic and structural changes** required to enable this. The current care environment also presents several challenges to delivering care that require close attention. There are pressures across the system, including recruitment and retention of staff, and integration of systems and processes across various parts of health and social care, which have an impact on how people experience care.

Dolors Comas reflected that Catalonia is at a different stage of development compared to Scotland and there are specific challenges related to commercial interests, precariousness of care work and a lack of effort to review outcomes and quality standards that acts as barriers. She noted that “Public administration focuses on technical requirements, not on evaluating results. Price is privileged over quality.” She highlighted an **urgent need for evaluation of the current system and co-creation of services**.

Comas further underlined the need to create awareness of the vulnerability experienced by people in the care sector, and highlight the value of care work as an integral component to ensure a functioning economy. She shared that **a lack of vision and strategic planning of care across the life course** means that programmes and actions are being developed in a fragmented way. She noted that this is dramatically visible in the excessive medicalisation of

care for older people and a lack of social care support around ageing.

Both Craig Morris and Dolores Comas highlighted that to enable change, strengthening **rights-based approaches and participation from those providing and receiving care** is key. It was also noted that there is an urgent need to **remove the stigma and negative perceptions** around social care, as well as strengthening **recognition and support for carers**. The role of **participatory processes** in better understanding needs and articulating a collective vision for care was also outlined as crucial for mobilising people in support of building a comprehensive system that assumes joint responsibility for care.

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## Key take aways:

1. There is no Right to Care without an integrated system of services, accountable groups, and associated budgets.
2. It is necessary to consider the diverse and evolving care contexts and needs of individuals at different stages of the life course.
3. Technology can play a key role in enabling management of everyday tasks which can free up time to focus on caring for the person. Human connection and interaction are irreplaceable.

4. Collective and community action are fundamental to designing transformative policies. Co-design and evaluation processes need to build in time and resources to enable genuine participation and ensure inclusion of diverse voices.
5. Carers need to feel recognised and heard, and self-organised groups and peer support networks offer collective tools for mutual support and empowerment.
6. Social and professional recognition are vital for improving the quality of work and care, which includes fair wages and recognition of carers' civil and legal rights.
7. There is a need for participatory processes for monitoring and evaluating outcomes and facilitating continuous learning, to ensure that policies meet the needs of the people they are designed to serve.



# Next steps

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The need to explore and improve care in/ with our communities has never been stronger. The Right to Care Network and the Glasgow School of Art have planned a series of activities and dissemination artefacts to be shared in the coming months, aligned with the conversations and reflections on care as a human right, and with an eye on organising a future event, involving political participation to develop ways of manifesting a rights based approach in the creation of our national systems of care. With the ongoing changes in the political landscape in Scotland and

Catalonia, we face a year of political and governmental uncertainty. This has made it challenging to identify a suitable date for a follow-up International Exchange on Right to Care event in Spring 2024, as initially envisioned. However, the success of this event has ensured that we remain enthusiastic about the project and its future. Building on the rich engagement that it facilitated, we plan to keep the dialogue going, with parallel programmes of work connecting care in each context, between Spring and Summer 2024.

Authored by:

Elba Mansilla, Sneha Raman, Lekshmy Parameswaran, Joanne Irvine, Xabier Ballesteros and Madeline Smith, with input from members of the Right to Care Network who contributed to organisation of the International Exchange on 16 December 2023.

Website: [dretacura.bcn.coop/](https://dretacura.bcn.coop/)

X: [@DRETaCURA](https://twitter.com/DRETaCURA)

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