Imperial College London

Palliate

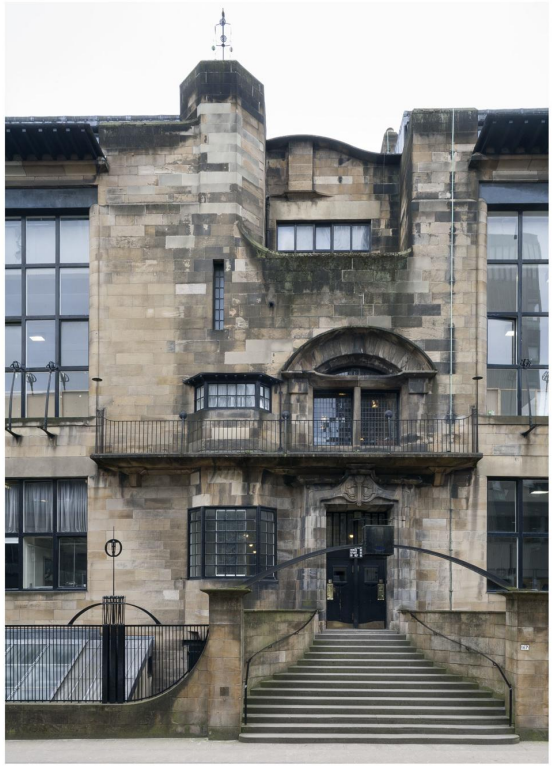
SPPC

May 2022

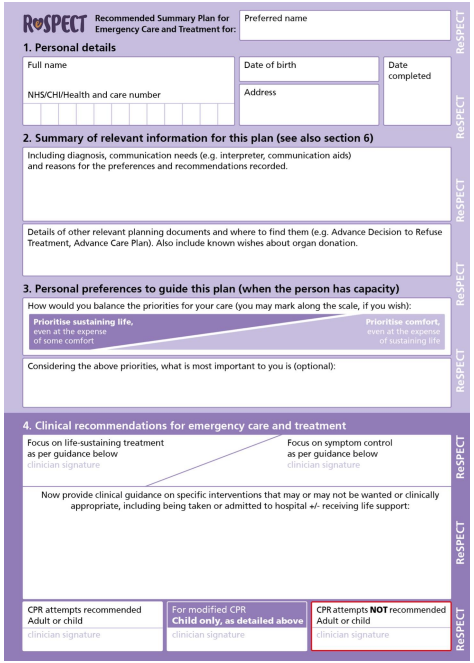
INSTITUTE OF GLOBAL HEALTH INNOVATION

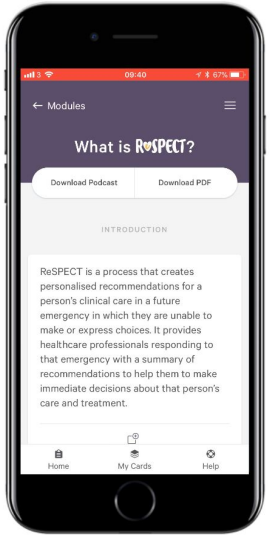
Who we are: an innovation team working in the clinical environment

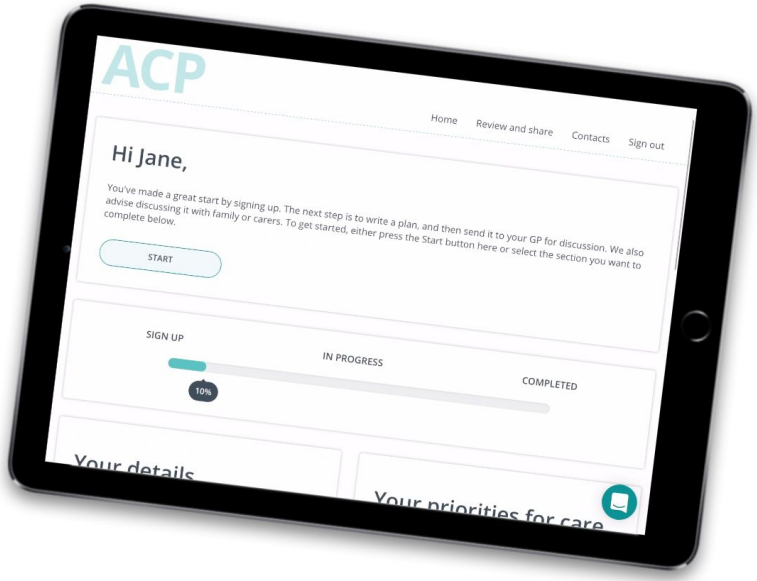
Lead for End-of-Life Care: Looking at the problem from a different point of view



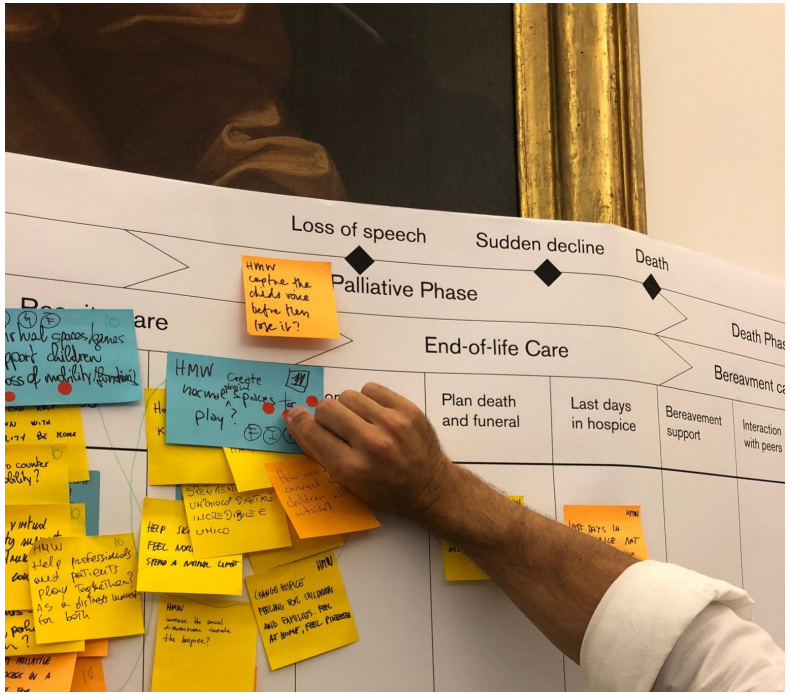
Who we are: our earlier work

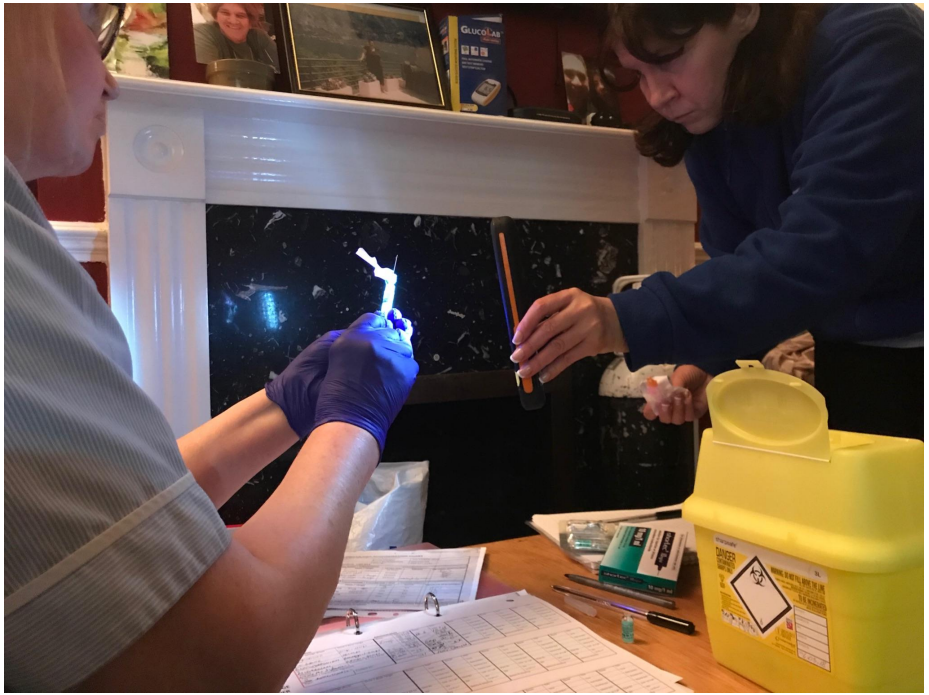






Who we are: discovering and exploring problems





The problem

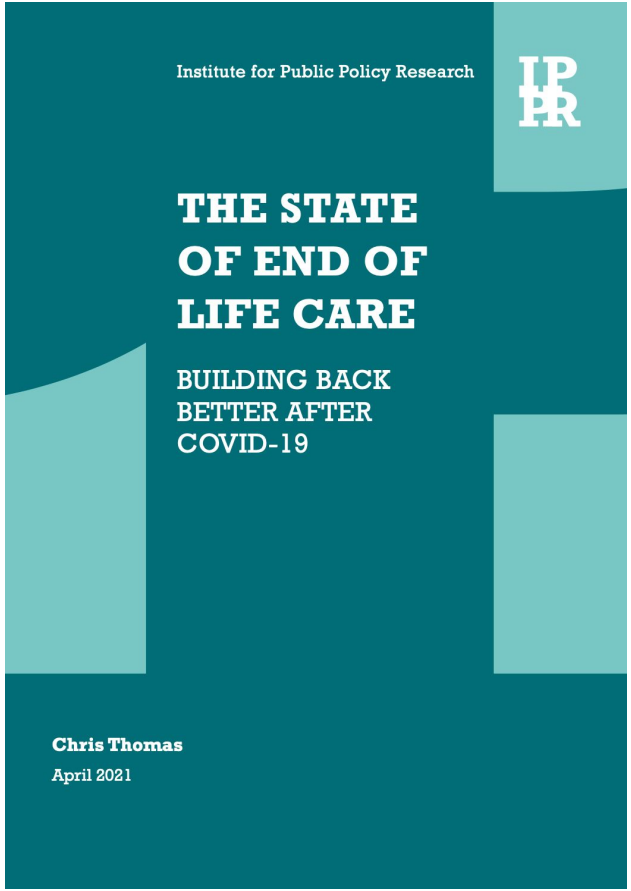
- The majority (92%) of the 500,000 people who die every year, would prefer to die at home, yet only a minority (23.5%) do die in their own home.
- Dying at home requires huge amounts of coordination, organisation and good communication to make things run smoothly.
- There is a hidden workforce of 500,000 laycarers - one for each person with a terminal illness - who make up the informal care system.
- But carers have a lack of knowledge around end-of-life care, which is a key barrier to decision making.
- Family members often ‘panic’ with changes to a person’s symptoms in the dying phase.
- Unmanaged symptoms at the end of life at home cause late admissions to hospital, denying families a home death

“It was the worst night of my life. I lay in bed holding my mother, stroking her as she was agitated and restless and trying to get up, delirious and restless, her eyes rolling back, all of us around the bed crying…. waiting for a nurse to come. We kept calling but no-one came. There was nothing I could do. By the time they came, she had died”
— Family carer

The opportunity

The 2021 IPPR report - developed with IGHI - outlined the case for community-led end of life care as the best, most sustainable alternative to a current reliance on hospitals, intensive treatment and low quality of life at the end of life.

It recommends providing everyone the right care, from the right person, at the right time.



INSTITUTE OF GLOBAL HEALTH INNOVATION

UNIL | Université de Lausanne

unisanté
Centre universitaire de médecine générale et santé publique · Lausanne

IPPR

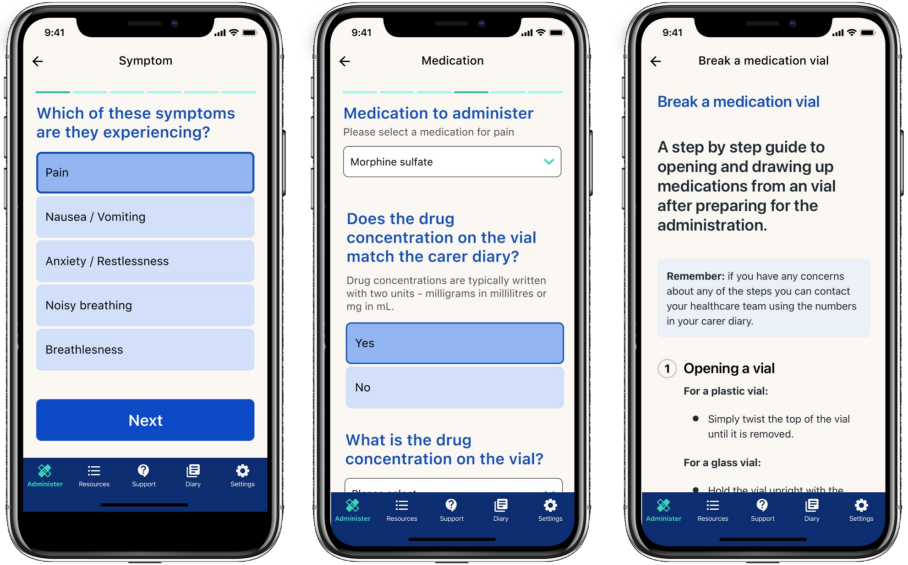
The opportunity

- **For patients**
  - Avoid unnecessary suffering with better managed pain relief and symptom control
  - Maintain preferences and priorities to stay and die at home
  - Maintain dignity by families sharing care with HCP's
- **For carers**
  - Improve understanding of symptom management and end-of-life experience
  - Improved confidence, autonomy and decision making
  - Lower chance of complicated grief after death
- **For professionals and health services**
  - Faster, more informed feedback about patient condition
  - Better utilisation of limited resources
  - Lower risk of hospital admissions, resulting in lower costs

The solution

Palliate is a digital platform to support people in the community as they look after loved ones in the last phase of their life.

It is comprised of medication administration recording and training, education and facilitation with on-demand professional support.



Our approach

Design

- Palliate is designed and built around the needs of patients and families, in close collaboration with carers and healthcare professionals.
- It is created using the lean startup cycle of *build-measure-learn*. Each component is built into a testable solution, which can be measured using data which informs the learning around development of further iterations.
- Our team of designers, developers, researchers and carer engagement leads means we can provide a holistic set of skills required to deliver for patients, families and healthcare teams.

Research

- Palliate is translated from existing studies in providing education and training for carers to administer medications.
- Our aim is to evidence both the need for better community palliative care and barriers to it (e.g HCP anxiety) and research the acceptability and effectiveness of Palliate as a digital intervention through feasibility studies.

Policy

- Working with CNWL NHS Trust on their new anticipatory medications policy
- Our team provides comprehensive training for HCP's on how to train and support the carer along with risk assessment tools and competency assessments
- Working across all levels of NHS management, we have developed a process that enables any community team to embed Palliate and deliver it to their patients.

Problems with existing medication administration practice

- There is no single national policy for carer administration of medications, different regions have different policies
- Those that do utilise complicated paper-based policies that are hard for carers to use, and offer little monitoring opportunities for professionals
- The NHS has a tendency to duplicate and needlessly amend existing policies makes efficient scaling impossible
- There is professional anxiety around perceived risk/types of drugs in the home, yet the anticipatory drugs are already in the home for nurses to administer

"I wanted clearer documents for recording, more carer-friendly, simpler. When you're tired it can be difficult to be clear about getting it ready and what you're giving."
— Family carer

Imperial College London

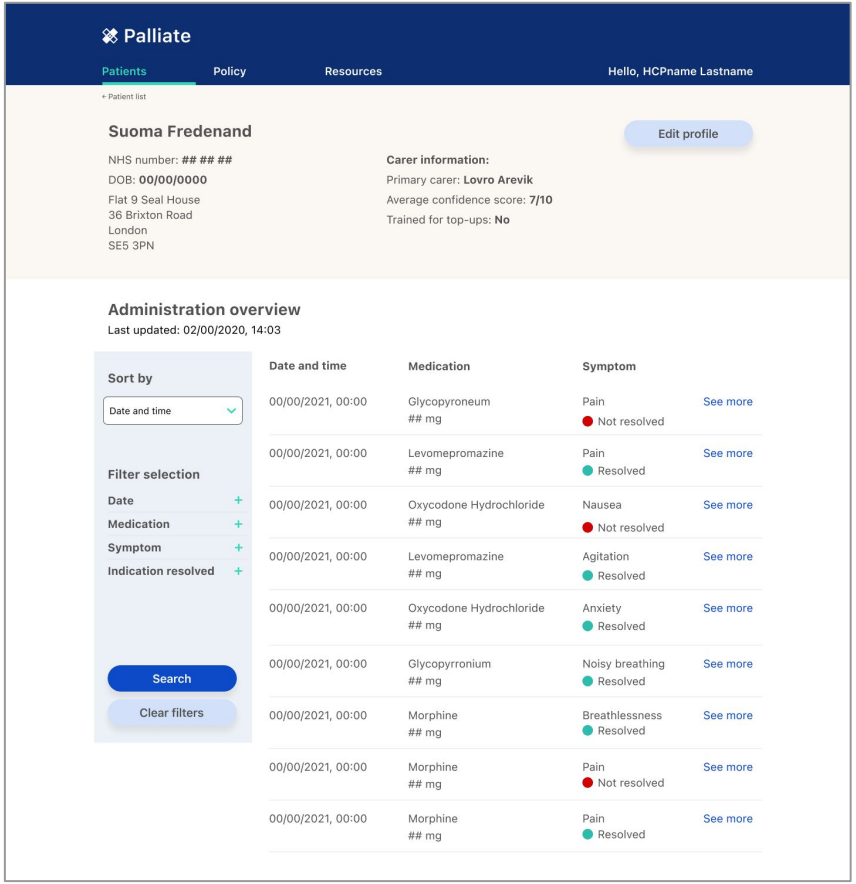
What does it do?

For carers

- Supports learning and understanding through educational resources, for both medication administration and beyond (last days/hours, after death, bereavement, self care)
- Assists with medication safety by providing the right information at the right time in the right format

For professionals (in the future)

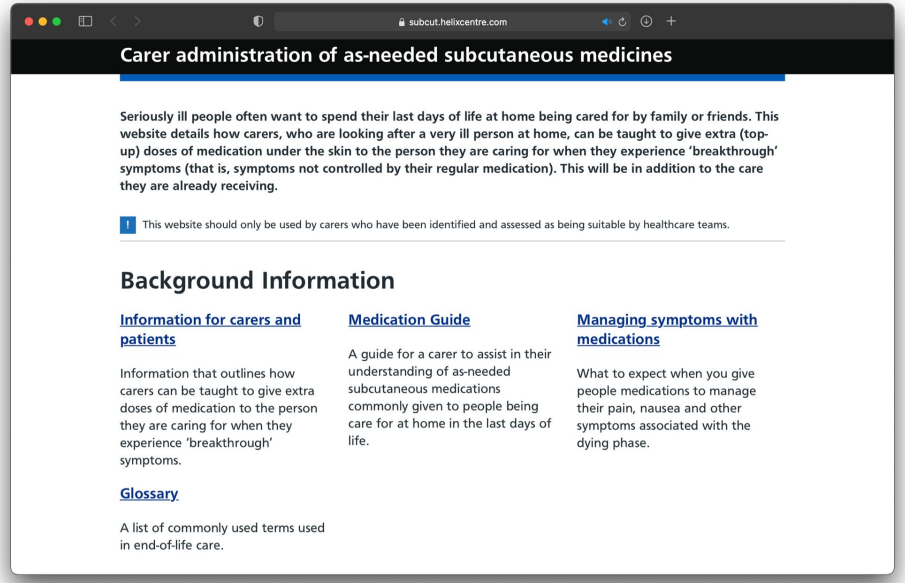
- Provides visibility of live data with multiple carers
- Monitoring and accounting of used/unused controlled substances
- Identify patients at risk of crisis and intervene to prevent problems
- Creating a direct link to CMC and LAS in London
- Integration with EHRs in Scotland and England



Palliate HCPView – currently in development

Why now?

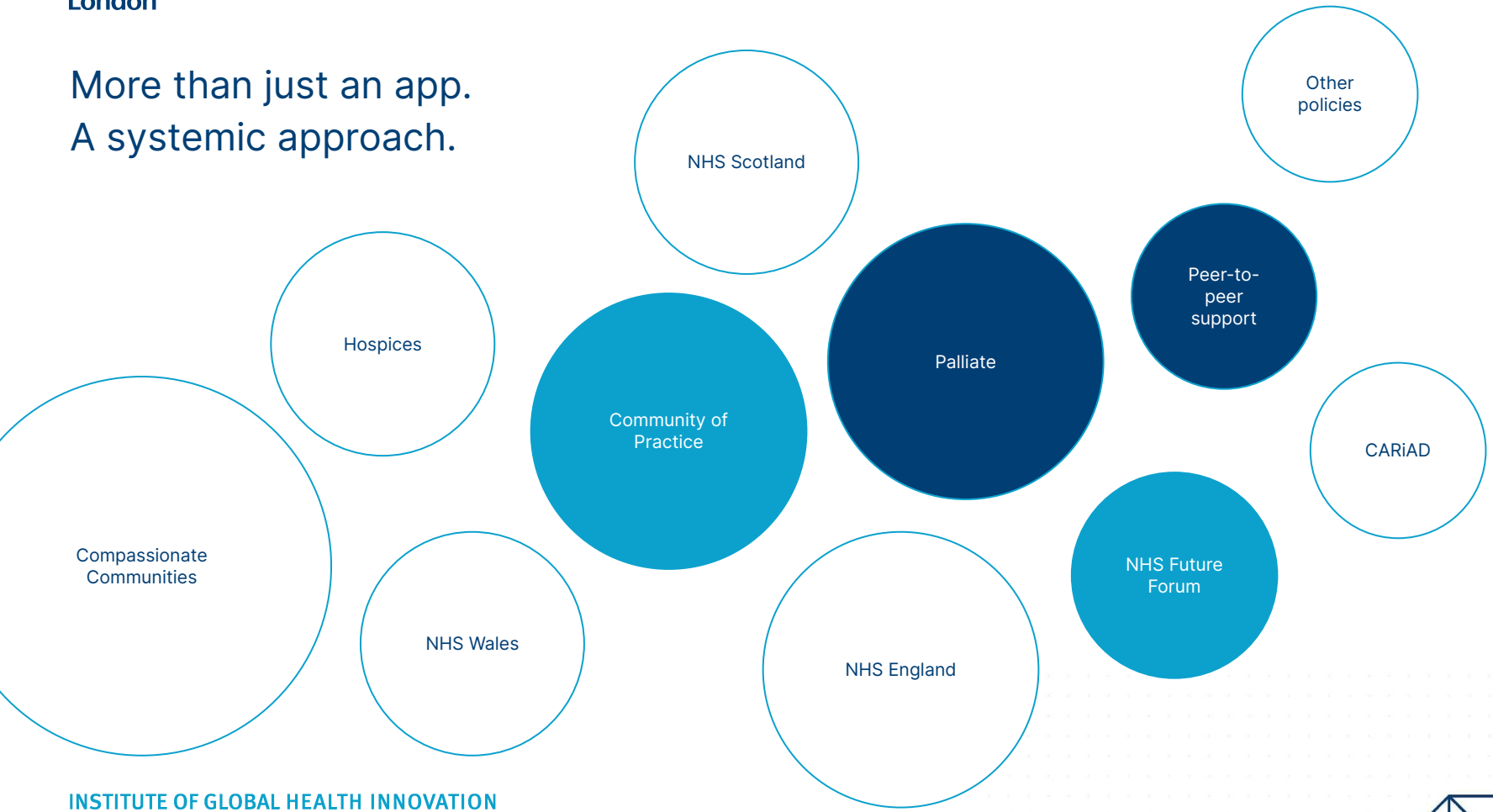
- There is little realistic prospect of meeting increased demand for home deaths using existing professional services[1]
- COVID-19 continues to re-write the way in which end-of-life care is done in the community: people have had to do more without professionals in the home
- In March 2020, our sub-cut medications website tool validated the role of design and technology to support better community palliative care and was used through UK during the first pandemic wave.



1. Abel J, Kellehear A. Palliative care reimagined: a needed shift. BMJ Support Palliat Care. 2016 Mar;6(1):21-6. doi: 10.1136/bmjspcare-2015-001009. Epub 2016 Jan 31. PMID: 26832803.

Imperial College London

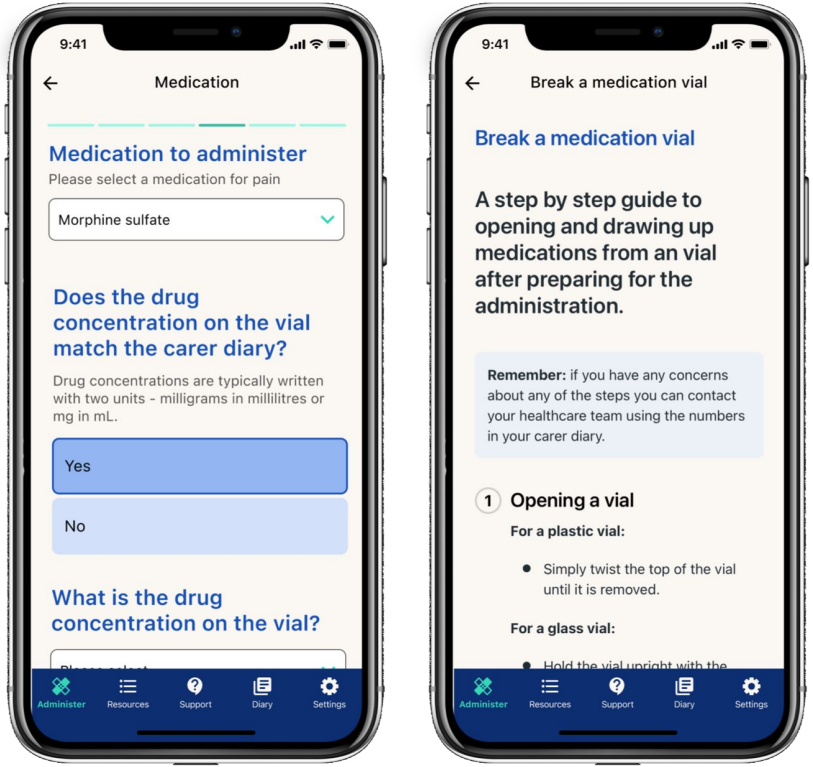
More than just an app.
A systemic approach.



Imperial College London

Our vision

To enable home deaths to be safely and effectively supported, with dignity and care for everyone.



If you think Palliate could work where you are, please get in touch with me to learn more

Thank you

ivor.williams@imperial.ac.uk